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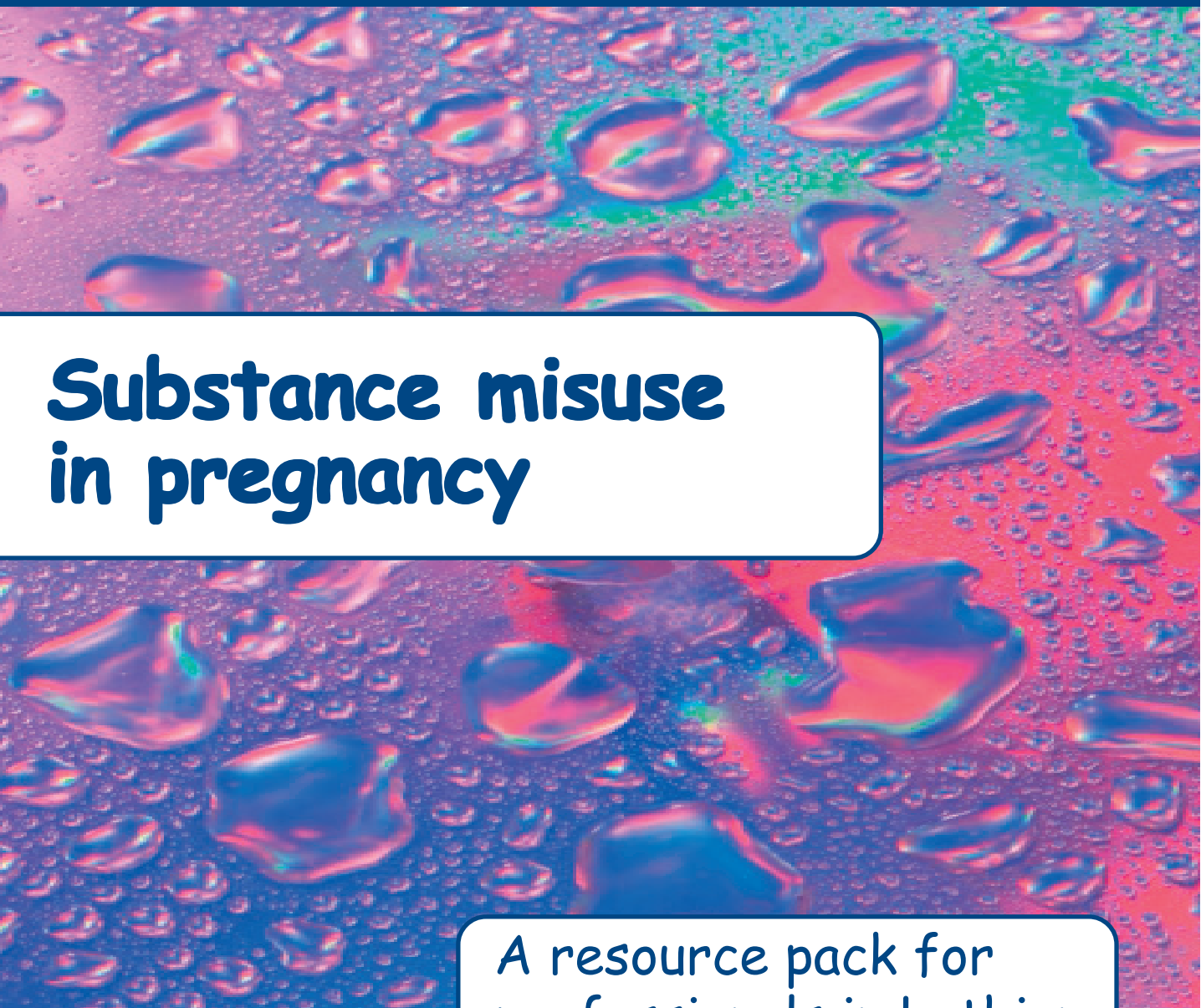

Substance misuse in pregnancy

A resource pack for professionals in Lothian

NHS
Lothian

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Health care staff in Lothian can also access and download this document from the intranet.

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Introduction

Introduction

Welcome to the ***'Substance Misuse in Pregnancy'*** resource pack for professionals working in Lothian. Many different professionals and service providers are now involved in the care of women who use drugs and/or alcohol during the course of their reproductive life. All professionals have an equally important role to play in ensuring a high standard of care is delivered. The pack aims to establish a **'framework for care'** so that all women who use drugs can be offered appropriate support before, during and after the birth of their child.

The framework for care consists of a **philosophy of approach** and **guidelines on good practice**. These are outlined in the pack and provide a basis from which the best possible outcomes can be achieved for both mother and baby. The pack takes a predominantly **community perspective**, as Lothian now provides most alcohol, drug and maternity services within the community setting.

A **broad view** of drug use is taken that includes *alcohol* and *nicotine*. This is because the risks of these drugs in pregnancy are well established and they are often used in combination with illicit and prescribed drugs (Johnstone 1998). Having said this, the pack refers mainly to the care of women who have *significant* problems related to drug and alcohol use. This is because *social and lifestyle factors* often complicate the **delivery of care** to these women. Their care often provides the biggest challenge for professionals and much co-ordination and understanding between services is needed.

The need for this resource pack was highlighted in the McIntosh (2001) needs assessment report *'The Care of Pregnant Drug and Alcohol Misusers in Lothian'*. Writing a new resource pack for all professionals (to replace the midwifery *'Substance Misuse in Pregnancy and Childbirth Resource Pack'* 1996) was one of a number of strategies recommended to improve the care of pregnant women with drug and alcohol misuse problems in Lothian. Disseminating the resource pack was seen as a useful way of improving joint working, outlining good practice and facilitating *multidisciplinary* training. Other recommendations included *improving liaison* by establishing a system of **'link midwives for substance misuse'**

throughout Lothian. This system has now been set up and is described in the pack. Obtaining more reliable data on the *nature and extent of the problem* in Lothian was also recommended. This has been achieved by designing new '**liaison forms**' that midwives and other health care professionals can now use to record important information as the woman progresses through maternity care. Producing good quality **information leaflets for service users** was identified as an important resource that needed to be developed. Two leaflets, written with the help of women service users, are included in the pack.

Currently in Lothian, there is no specialist midwifery service for pregnant women who have drug and/or alcohol related problems and no plans to establish one in the near future. Other areas (notably Glasgow, Liverpool, Manchester and London) have developed specific midwifery services for this client group. Whilst it has been useful to learn from these other areas, it is important to remember that Lothian is different for a number of epidemiological, geographical, organisational, professional and cultural reasons.

Lothian has a long history of providing drug, alcohol and maternity care within the community setting. **Harm reduction** and **normalisation** has been at the heart of our approach since the 1980's. A number of professionals in Lothian have taken a special interest in this field and we have built up considerable expertise over the years, taking care not to establish services that might *segregate* or *stigmatise* women with substance misuse problems. Areas of good practice exist within Lothian, for instance in Craigmillar, where antenatal services are jointly managed by midwifery and obstetric staff, general practitioners, health visitors, and drug specialists who all work together in the one centre. The majority of health and social care workers in Lothian have integrated work with this client group into their normal client population despite the additional needs with which they often present. Midwifery and other services have recognised the *special needs of this client group* and have developed strategies designed to improve access to care as well as communication and joint working. This resource pack reflects the ideals of care that can be achieved.

Please note:

1. The **terminology** used in this resource pack has been carefully chosen so as to avoid language that implies value judgements or has negative connotations. For instance, the terms '*drug and alcohol dependency*', '*drug and alcohol related problems*', '*drug use*' or *'substance misuse'* are used in preference to terms such as '*addiction*', '*drug addict*', '*alcoholic*', '*drug habit*' or '*drug abuse*'. The use of currently preferred terminology is especially important when working with substance-misusing women who are particularly sensitive to public and professional judgements.

2. The information and advice in this resource pack is based on current *best practice* and available *evidence*. Sources include: governmental policy documents, contemporary social theory and health care practice, good practice guidelines, expert opinion and recent publications from experienced practitioners in the field as well as a literature and publications search.

3. The resource pack is **not fully referenced** but those references that are cited are recommended for further reading. Other helpful sources of information, addresses and websites are included in the pack. A **glossary** provides definitions of terms and a list of Lothian **services** is also included.

4. The resource pack is not designed to be read cover to cover but it is worth taking a little time to familiarise yourself with the layout and contents so that you can access information easily when you need to. It is worthwhile reading the **'key points'** and **'philosophy of approach'** before other sections.

5. This resource pack is **copyrighted**. Professionals are welcome to reproduce the contents in full or in part, as long as the source is acknowledged. Many of the appendices are designed for photocopying.

Key points

Key points

- Most pregnant women with substance misuse problems will have a normal pregnancy, labour, delivery and a full-term normal birth-weight baby. Most will embrace motherhood and cope well with caring for their children.
- Many conditions carry with them an element of risk or uncertainty during pregnancy and require greater care. Increased risks are associated with smoking, alcohol use and drug use in pregnancy. Agencies should work together to offer information, advice, treatment and care that will help reduce these risks.

Philosophy of approach

- Many factors affect pregnancy outcome and the health and development of infants and children. Substance misuse is just one factor. A holistic assessment and package of care needs to be offered. The woman's lifestyle and social circumstances, her physical and psychological needs, her support needs, as well as the needs of her unborn child should be taken into account.
- The approach taken by professionals is a crucial factor in the delivery and outcome of care. Pregnant women with substance misuse problems are subject to social disapproval and judgemental attitudes. Discriminatory professional practice deters women from seeking help. Professionals need to encourage women to engage with helping agencies and ensure that their approach to care is based on good evidence and best practice.
- The guiding principle of management should be a pragmatic approach that emphasises harm reduction and aims to achieve the best possible outcome for both mother and baby. This means taking account of the woman's wishes, recognising her vulnerabilities and needs and focusing on what *could* be done rather than what *should* be done.
- A well co-ordinated multi-disciplinary and multi-agency approach will ensure that a comprehensive package of care can be offered. All professionals involved in a woman's care need to communicate with one another to ensure that they share a common approach, offer consistent advice and are working towards the same goals.

Pre-conceptual care

- Agencies in contact with substance-misusing women should routinely enquire if they plan to have children. All agencies have a part to play in offering pre-conceptual advice and care.

Antenatal care

- All pregnant women with substance misuse problems and their partners should be told about the benefits of antenatal care and encouraged to attend early in pregnancy.
- Specific information and advice about the effects of drug use (including tobacco and alcohol) on pregnancy should be routinely given to all women identified as having a substance misuse problem.
- Drug dependent women should be given information and advice on Neonatal Abstinence Syndrome and helped to prepare for the care of their newborn baby.
- Pregnant women and their partners should be given priority access to drug and alcohol treatment services. Treatment goals should be realistic and tailored to their individual needs.

Assessing risk in pregnancy

- Professionals should undertake a continuous risk assessment throughout pregnancy to identify any problems that could affect the mother, her pregnancy and the well-being of the baby.
- Substance misuse is not sufficient reason in itself, to assume that parenting or child care will be inadequate. However, the safety and welfare of the newborn baby is paramount and professionals should follow child protection guidelines if 'significant harm' is likely.

Intrapartum care

- Although most women with substance misuse problems will have a normal labour and delivery, they may need help to prepare for hospital admission. Drug dependent women should be reassured that they will be given adequate pain relief during childbirth.
- Following delivery, parents should care for their baby as normal in the postnatal ward. Separating mother and baby should be avoided wherever possible. Like other women, they should be encouraged to breastfeed, bond and care for their baby.

Postnatal care

- Parents with substance misuse problems may need considerable help and support to cope with the transition into parenthood. Planned support that continues into the postnatal period is crucial.
- The postnatal period can be a stressful time for parents. For mothers who have managed to reduce their drug and alcohol use during pregnancy, the risk of relapse to former levels of drug taking is high. Relapse prevention work, careful drug management and intensive psychosocial support may be required for some time.

Setting the scene

Setting the scene

The extent of the problem

The true extent of drug taking in women is largely unknown as reliable figures are hard to obtain. It is clear, however, that smoking, alcohol use and illicit drug use in women of reproductive age is increasing and the continued use of drugs during pregnancy is common. Approximately one-third of pregnant women smoke and approximately 60% continue to consume alcohol (Taylor 2003). The use of illicit drugs in pregnancy such as cannabis, amphetamines, heroin and cocaine is thought to be fairly widespread, especially in large urban areas. For many women, drug use is a 'lifestyle choice' and a fundamental part of their lives.

Although nicotine and alcohol are legally available it is important not to confuse **legality** with **safety**. Maternal use of tobacco is well researched and known to have significant harmful effects on pregnancy. Although approximately 20% of women who smoke manage to give up during pregnancy, nicotine remains the most problematic drug of use in pregnancy at a population level (Johnstone 1998). Alcohol has the clearest association with *teratogenesis* (congenital birth defects), with well-documented adverse effects associated with high maternal intake. Approximately 20% of women of reproductive age exceed the recommended weekly limit of alcohol consumption (Scottish Executive 2002). Nicotine and alcohol are often used in combination with other drugs and most women who present to drug and alcohol treatment services report *'polydrug use'.*

National statistics and local data sources provide some indication of the prevalence of pregnant women who have significant drug and alcohol related problems. The Information and Statistics Division (ISD Scotland) collects national statistics on drug misuse during pregnancy. The source of the data is maternity in-patient and day case records (SMR02) and neonatal discharge records (SMR11). Drug misuse is recorded using codes from the International Classification of Diseases (ICD-10) criteria. A revised SMR02 now includes data items for documenting alcohol consumption and SMR11 is currently being replaced by the Scottish Birth Record (SBR), which has the potential to collect more detailed information about maternal drug and alcohol use.

These data sources have traditionally suffered from under-reporting and the statistics are thought to grossly *underestimate* the prevalence of drug misuse. Nevertheless, some useful information has been gathered which shows that the majority (approx 80%) of live births to women with a recorded history of drug misuse, have resulted in the spontaneous delivery of full-term normal birth weight babies (Drug Misuse Statistics Scotland 2002).

In Lothian, a significant number of women (approximately 1000) are now on prescribed drugs for the treatment of their drug dependency and most are of reproductive age. Informal recording methods (using midwifery 'liaison sheets') have estimated: approximately 100 pregnancies per year in women who have significant substance misuse problems; approximately 40 babies per year receive treatment for conditions related to maternal substance misuse. This number is likely to increase as the overall prevalence of substance misuse increases. Improved local data collection methods have recently been implemented in Lothian. Maternity staff now complete *substance misuse liaison forms* for all pregnant women who report problem drug and alcohol use. The liaison forms are included in *appendix 9*.

The nature of the problem

Many factors affect the outcome of pregnancy and the health and well-being of mother and baby. Many conditions carry with them an element of risk or uncertainty and require greater care during pregnancy. Drug use is just one factor. Other factors include lifestyle and social circumstances, physical and psychological health, nutrition, breastfeeding, sexually transmitted and communicable diseases, antenatal and postnatal care.

Women who seek help for drug and alcohol related problems are more likely to be unemployed and living in areas of *social deprivation*. Pregnant women with substance misuse problems often present with a *multiplicity of needs* that require the involvement of many different professionals and agencies. The *organisation* and *delivery* of care therefore, is an important factor in outcome.

Organisational difficulties

Professionals who are experienced in working with this client group often report a number of problems. These include:

- No common or 'shared' approach to care
- Lack of understanding of professional roles and responsibilities
- Poor liaison and communication between professionals
- Little consultation or 'joint' assessments
- Limited 'partnership' of care with the woman
- Unrealistic expectations and treatment goals
- Inconsistent and contradictory advice
- Difficulty organising care plan meetings or reviews
- Little engagement or involvement of the partner
- No *one* professional taking responsibility for co-ordinating care

For **midwives**, delivering care to this client group can be very time consuming. In Lothian, community midwives each manage approximately 80 pregnancies per year in their geographical area. Committed midwives can often spend considerable time co-ordinating care, liaising with other professionals, organising antenatal and postnatal care planning meetings, organising the additional antenatal care requirements that these women often need, and visiting in excess of 10 days postpartum.

In addition to the organisational and service delivery difficulties there are a number of other reasons why the care of pregnant women with drug and/or alcohol related problems has been difficult for health and social care providers.

Ideology

The prevailing societal view of women with substance misuse problems is a negative one. Drug and alcohol dependent women have been characterised as irresponsible, inadequate, deviant, immoral and unfit for motherhood. Research shows that women who are drug or alcohol dependent get significantly more social disapproval than men (Klee, Jackson & Lewis 2002). In pregnancy, this view is heightened as the welfare of the unborn child is emphasised and assumptions are made about the harmful consequences of the mother's drug/alcohol use and her ability to be a 'good mother' and care adequately for her child (Macrory & Crosby 1995). This gender bias has led to punitive responses, unacceptable levels of

surveillance and restricted options for treatment and care (Klee, Jackson & Lewis 2002). Negative societal views and professional attitudes coupled with discriminatory practice have deterred women from seeking help. They may appear to neglect their condition and that of their babies but in reality it may be the service's attitudes and approach that have excluded them from care (Morrison 1999).

Research evidence

Lack of good data and research evidence on the effects of illicit drug use on the fetus and baby has led to some confusion and exaggeration of risk. Providing balanced and factual information to women so that they can make informed choices in pregnancy has proved difficult and women continue to receive inconsistent and contradictory advice.

Women's fears

Not surprisingly, pregnant women who have substance misuse problems frequently report a number of concerns (Scottish Executive 2003) including:

- Fear that child protection agencies will be contacted automatically
- Fear that her baby will be taken into care
- Fear and confusion over whether her drug use will cause fetal damage
- Fear that she will be blamed if anything goes wrong with her pregnancy
- Fear of being thought of as un uncaring or 'unfit' mother if she doesn't manage to come off or reduce her drug use
- Feeling guilty and 'to blame' for her baby experiencing withdrawal symptoms

Poor social circumstances

Drug and alcohol related problems are commonly associated with *socio-economic deprivation* and poor social circumstances. These include:

- Poor support from family and friends
- Poor support from a substance-misusing partner
- Drug related criminal activity and legal problems (e.g. outstanding charges, impending court cases, community service order, probation, prison history, drug treatment and testing orders)
- Violence (e.g. substance misuse-related or domestic abuse)

- Financial problems (including debts, fines and problems with welfare benefits)
- Housing problems (including homelessness, insecure or unsuitable housing)

Maternal health problems

Injecting drug use and *harmful levels of drinking* are associated with poor maternal health. This may include:

- Malnutrition and anaemia
- Respiratory problems
- Poor dental hygiene
- Blood borne virus infections (HIV, hepatitis B, hepatitis C)
- Complications from injecting (such as abscesses, endocarditis, septicaemia etc)
- Liver disease
- Accidental injury
- Overdose and maternal death
- Mental health problems (such as anxiety, depression, self harm, psychosis)

Chaotic lifestyle

Drug and alcohol related problems are commonly associated with a *chaotic lifestyle* and may result in the woman receiving *poor maternity care*. For example:

- Late pregnancy booking
- Poor attendance for antenatal care
- Not registering with a general practitioner
- Poor attendance for parenthood education
- Late presentation during labour
- Early discharge home after delivery

Obstetric and paediatric problems

Drug use (including alcohol and tobacco) impacts on *obstetric* and *paediatric* morbidity and mortality. Increased rates of *low birth weight, pre-term delivery*, *Sudden Infant Death Syndrome* (SIDS or 'cot death') and *Neonatal Abstinence Syndrome* in babies are the most commonly reported problems. The effects of specific substances on the developing fetus and baby are outlined later in the pack (see page 35).

It is well established that many obstetric problems associated with substance misuse *are also* associated with social deprivation, poor antenatal care, poor maternal health and nutrition (Mounteney 1999). A number of case controlled studies have found comparable outcomes in women (who are matched by age, parity, social deprivation category etc) who *do not* have substance misuse problems (Siney 1999). Social factors, as well as the quality of health and social care provision, significantly influence the health and well-being of both mother and baby.

Because of such complications, *substance misuse in pregnancy* has become one of the leading conditions requiring specific guidelines and strategies.

The next section outlines the principle guidelines that form a '*framework for care*'.

Framework for care

Framework for care

A number of recent governmental publications have provided a broad set of principles and guidelines on good practice for working with pregnant women and families affected by drug and alcohol related problems. These include:

- *'Drug Misuse and Dependence – Guidelines on Clinical Management',* Annex 5: *'Pregnancy and Neonatal Care'*, Department of Health (1999)
- *'A Framework for Maternity Services in Scotland* ', Scottish Executive (2001)
- *'Integrated Care for Drug Users'*, Effective Interventions Unit (2002)
- *'Plan for Action on Alcohol Problems',* Scottish Executive (2002)
- *'Getting Our Priorities Right'*, Scottish Executive (2003)
- *'Hidden Harm: responding to the needs of children of problem drug users'*, The Advisory Council on the Misuse of Drugs report (2003)

Philosophy of approach

The philosophy of approach outlined here reflects the central themes from these policy documents as well as recommendations from leading experts in the field.

Overall, the approach to care needs to be:

- ✓ women and family centred
- ✓ non-judgemental
- ✓ pragmatic, with an emphasis on harm reduction
- ✓ holistic
- ✓ provided by a multi-disciplinary and multi-agency team

Women and family centred approach

Pregnancy and the transition into parenthood is a significant life event. For women who have problems related to alcohol and drug misuse it offers **opportunities** as well as **risks**. These women have the *same hopes and aspirations* for family life and the same anxieties about pregnancy, childbirth and motherhood as other women (Ford & Hepburn 1997). For service providers, the challenge is to offer the right kind of support that will allow them to *minimise the risks* as much as possible and to *make the most of available opportunities*. This means that treatment and care needs to be *women* and *family centred*.

The important role of **partners** needs to be recognised, and professionals need to ensure that, where appropriate, they are encouraged and supported to take a full and active role in pregnancy, childbirth and postnatal care. Women and their partners need to be able to make fully **informed choices** about their care. They need timely, relevant and *easily accessible* information to help them make the choices they face. They also need *prompt access* to any treatment and care that they might need.

Maternity care should be tailored to the needs of the individual woman and her family, focusing on the **safety of mother and baby**. It should take into account:

- ✓ the needs and wishes of the woman and her family
- ✓ her right to privacy and dignity throughout her pregnancy
- ✓ her cultural values, beliefs, attitudes, and chosen lifestyle

A *family centred approach* will create an atmosphere of **normalisation** and **partnership** that will engage the woman and her partner and foster the best possible outcome for mother and baby.

Non-judgemental approach

Service providers need to adopt a truly professional approach that is not led by views which are distorted by prejudice or limited by conventional stereotypes (Klee, Jackson & Lewis 2002). Professionals need to continually examine their approach to care so that they can account for their practice in terms of what is in the best interests of the woman and her baby and what is in accordance with the *best available evidence* and *best practice*.

Establishing **early contact** with pregnant women who have substance misuse problems and **retaining them in treatment** and care is vital. This can best be achieved by creating a *non-judgemental environment*. Providing care with compassion, reassurance and encouragement will facilitate good contact. A non-judgemental approach is also a pre-requisite for obtaining the necessary details of the woman's substance misuse and social circumstances. The woman needs to feel *supported* throughout her pregnancy and beyond. This means that professionals need to create a *positive pregnancy experience* for the woman, irrespective of risk and despite any difficulties that she may have.

Harm reduction approach

Substance misuse in pregnancy is associated with increased risks. Pregnancy therefore provides an excellent opportunity for professionals to provide education and care within a *harm reduction framework* (Johnstone 1998). Harm reduction is a **pragmatic** approach to care which aims to reduce the harm to individuals and society whether or not it is possible to reduce the substance use *per se*. It is essentially a *public health policy* designed to minimise risk. It is a *reality-based* approach that focuses on what *could* be done rather than what *should* be done. A harm reduction approach includes providing the means, information and education to enable people to make informed choices about their lifestyle.

Treatment and care goals must be **realistic** and tailored to the needs of the individual woman. Pressurising pregnant women into reducing or coming off drugs may lead to more harm than good. A **flexible** service that is able to take account of the wishes of the woman and support her to make her own decisions and be guided by what she feels she can achieve, will be most successful (McIntosh 2001).

It is important to remember that a harm reduction approach *includes abstinence*. Abstinence can be helpfully thought of as the 'final goal' of harm reduction and one which many people with substance misuse problems may wish to achieve. Drug and alcohol *dependency* however, is considered a chronic relapsing condition. People may use drugs and alcohol in potentially harmful ways for *many* years before achieving abstinence. *Long-term support* to help people *minimise the harm* associated with substance misuse is normally required and may include such interventions as: substitute prescribing; needle exchange; and safer drug use / sensible drinking advice and support.

Holistic approach

Pregnant women with substance misuse problems often present with a *multiplicity* of needs and their substance misuse is just one aspect of their lives. A *holistic approach* to care, from preconception to parenthood, needs to be offered. A **holistic assessment** should aim to identify their physical, psychological and social needs. It encompasses the *context* and *causes* of their problems and addresses the needs of other family members (Scottish Executive 2002). A **holistic package of care**

recognises that a woman's needs are inter-related and aims to provide a service that can address not just one aspect of her care, but all her needs and current strengths.

Multi-disciplinary and multi-agency approach

Pregnant women, whose drug or alcohol use is likely to impact on the outcome of their pregnancy, will need a comprehensive service provided by a multi-professional team. This service should provide **consistent** advice and support and **continuity** of care and aim to ensure safety for both mother and baby.

Many women will benefit from receiving care from a range of health and social care providers. This *'multi-agency' approach* to care needs to be **well co-ordinated** and **integrated**. Good communication between professionals is central to the provision of good quality care. Integrated care is where everyone involved in the provision of care has a **shared philosophy of approach**, knows what each other is doing and saying, and also knows what the woman herself wants.

A clear understanding of *professional roles and responsibilities* is needed to maximise the quality of care. Collaborative working should minimise the opportunities for contradictory or opinion-based advice and practice. Professionals delivering care need to have the *knowledge and skills* necessary for the type and level of service they provide. They should be aware of the expertise of other professionals and be prepared to draw upon that expertise where needed.

Pregnant women with substance misuse problems should receive the same quality of care, respect and dignity as any other pregnant woman throughout their pregnancy. The philosophy of approach outlined above and the guidelines on good practice that follow should ensure that this can be achieved.

Guidelines on good practice

Guidelines on good practice

This section of the resource pack outlines *guidelines on good practice* for working with pregnant women who have substance misuse problems.

The care process

It is important that all professionals involved with substance-misusing women follow a clear '**pathway of care'**, from pre-conception through to parenthood. A model 'care pathway' is included in *appendix 4*.

The care process involves *assessment*, planning care and agreeing an individual *care plan*, *implementing* care, and *reviewing* care. These key tasks in the care process are outlined below, along with a *checklist* of topics that are relevant to each stage of the process, many of which are covered in the course of routine health care as well as drug and alcohol treatment and social care service provision.

Assessment

Assessment should be **holistic** and **continuous** throughout pregnancy. It should take into account the woman's physical and psychological health needs, her social circumstances, her partner's drug and alcohol use, an assessment of risk as well as her own drug use (including alcohol and tobacco). *It may involve a number of different professionals contributing to the assessment process over time*, including the General Practitioner, midwifery, obstetric and paediatric staff, the Health Visitor, Drug and Alcohol Worker and Social Worker.

An assessment of **physical health needs** should include such topics as:

- ✓ Past obstetric / gynaecological history
- ✓ General health status
- ✓ Nutrition (e.g. diet, weight, anaemia)
- ✓ Dental health
- ✓ Exposure to infections (e.g. Blood Borne Viruses, Sexually Transmitted Infections)
- ✓ Complications from injecting (including venous access)
- ✓ Accidents or injuries
- ✓ Difficulty getting registered with GP

An assessment of **psychological needs** should include such topics as:

- ✓ Worries or concerns about pregnancy (e.g. fear baby will be taken into care, fear of damage to the fetus)
- ✓ Current or past anxiety related problems
- ✓ Current low mood or history of depression / self harm
- ✓ History of eating disorder (e.g. anorexia or bulimia)
- ✓ Low self esteem or self worth
- ✓ History of physical, emotional or sexual abuse
- ✓ Bereavement issues
- ✓ Woman's perception of her own circumstances, needs and coping ability

An assessment of **social needs** should include:

- ✓ Housing situation (e.g. homelessness, insecure or unsuitable accommodation)
- ✓ Financial situation (e.g. debts, rent arrears, unpaid bills or fines)
- ✓ Legal situation (e.g. current charges, impending court cases, community service or probation orders, drug treatment and testing orders)
- ✓ Employment or training & education issues
- ✓ Care of any existing children
- ✓ Parenting skills
- ✓ Relationships with partner, family, friends
- ✓ Available social support network
- ✓ Contact with other health and social care workers

An **assessment of drug use** should include the following:

- ✓ Smoking
- ✓ Alcohol use
- ✓ Illicit (street) drug use
- ✓ Injecting drug use
- ✓ Prescribed drug use
- ✓ Use of 'over the counter' medications
- ✓ Current contact with specialist drug/alcohol services
- ✓ Current treatment and care goals
- ✓ Previous contact with drug/alcohol services

Information on the effects of drugs on the developing fetus and baby, as well as the assessment and management of drug use in pregnancy is described in detail later in the pack (see pages 31-63).

An assessment of the **partner's drug use** should include:

- ✓ Partner's current use of tobacco, alcohol and drugs
- ✓ Level of stability if drug dependent
- ✓ Is partner currently injecting drugs?
- ✓ Blood borne virus (HIV, HCV, HBV) status?
- ✓ Partner's current contact with health and social care agencies

A **risk assessment** should include:

- ✓ Obstetric / gynaecological problems
- ✓ Current maternal health problems
- ✓ Domestic abuse
- ✓ Previous history of child care problems
- ✓ Impact of substance misuse on lifestyle
- ✓ Impact of drug culture environment
- ✓ Social isolation / unsupported pregnancy

Care planning

Care should be planned in **partnership** with the woman and, where appropriate, her partner. Care planning involves developing a '*package of care*' that meets the woman's needs and **takes account of her views and wishes**. It includes what treatment and care will be provided, and by whom, as well as the desired outcomes. Care plans need to be *realistic* and *achievable* and they should include a *date for review* (Whittaker & McLeod 1998). This should be arranged for between 28-32 weeks gestation.

A **care plan** would include some or all of the following:

- ✓ Antenatal care including screening tests, scans, monitoring of fetal growth
- ✓ Treatment and care of substance misuse (realistic harm reduction goals and strategies)
- ✓ Plan to address any social needs
- ✓ Plan to meet and involve the partner in care (where appropriate)
- ✓ Preparation for parenthood (including parent education classes)
- ✓ Preparation for childbirth (labour and delivery)
- ✓ Preparation for Neonatal Abstinence Syndrome (if drug dependent)
- ✓ Preparation for infant feeding (support & encouragement to breastfeed)

- ✓ Plan for postnatal care (including preparations for infant and social support)
- ✓ Plan to address any risks or concerns associated with parenting skills or child care
- ✓ Plan to involve other professionals and referral to other agencies
- ✓ Plan for multi-disciplinary / multi-agency meeting / child protection case conference

Reviewing the care plan

The *care plan* and *progress of care* need to be reviewed at *regular intervals* throughout the pregnancy (for example at each antenatal appointment).

Women with identified risks or multiple social needs may benefit from attending an organised 'care plan review' meeting. All parties involved in the delivery of care should be encouraged to attend review meetings or submit a brief report. If the care plan review meeting takes place around 28 weeks gestation then there will be enough time for services to be put in place in time for the arrival of the baby.

The **review process** should include a discussion on the following topics:

- ✓ Attendance for antenatal care?
- ✓ Fetal health and development?
- ✓ Maternal health? (including mental health)
- ✓ Current smoking/alcohol/drug use?
- ✓ Attendance for other health care appointments? (e.g. GP, Health Visitor or Community Mental Health Nurse)
- ✓ Attendance at specialist drug/alcohol service?
- ✓ Attendance for social care appointments? (e.g. social work, voluntary sector agencies)
- ✓ Involvement and support of partner?
- ✓ Stability of lifestyle?
- ✓ Improvement in social circumstances?
- ✓ Current or potential risks?
- ✓ Future needs to address?
- ✓ Future goals to work towards?

Care management

Some women with substance misuse problems and their families will have *complex* health and social care needs and will require a *care management* approach and a *comprehensive package of care* during pregnancy and well into the postnatal period. In these cases, one professional needs to be identified as the '*care co-ordinator*' to take responsibility for managing the care process. The role of this '***lead professional***' is to ensure that the care process is fully documented, implemented and reviewed. This requires good liaison, communication and organisational skills to ensure a continuum of care is delivered in accordance with the agreed care plan for the family.

Consent to share information with other professionals

All professionals working with pregnant women who have substance misuse problems need to work *collaboratively* with other professionals and agencies in order to provide good quality care. It is important to discuss 'joint working' with the woman at an *early stage* so that **informed consent** can be obtained to allow information sharing. Most women are happy to agree to this once the benefits of inter-agency collaboration are explained. Information regarding her assessment, care plan and progress can then be exchanged between professionals.

Although the woman may consent to 'joint working' she may still need reassurance about her right to privacy and should be given guidance on the Data Protection Act (1998) and the terms of professional **'confidentiality'**. This will include advice about circumstances whereby confidentiality may be breached e.g. for child protection, mental health or legal reasons. A *proforma* **consent form** is included in *appendix 5*. The consent form can be photocopied and sent to all professionals involved in the woman's care (i.e. the Midwife, GP, Health Visitor, Drug/Alcohol worker, Social Worker etc).

Information and guidelines on drug use

Information and guidelines on drug use

Ideally, all professionals who provide care to pregnant women with substance misuse problems should be able to:

- ✓ Provide information on the risks associated with drug use in pregnancy
- ✓ Assess drug and alcohol related problems in pregnancy
- ✓ Provide advice about how to manage drug use in pregnancy
- ✓ Discuss substance misuse treatment and care options for pregnancy

If professionals cannot provide the above then they should ensure that they refer women to services that can.

The next section of the resource pack provides information and *guidelines on good practice* on these topics.

Trends in substance use (illicit and prescribed)

This section of the resource pack includes basic information on commonly used drugs in Lothian for those professionals not familiar with illicit (non-prescribed) and prescribed drug use.

Commonly used drugs in Lothian include:

- **cannabis** ('hash' and marijuana)
- **stimulants** (such as amphetamine, cocaine, ecstasy)
- **hallucinogens** (e.g. LSD & 'magic mushrooms')
- **opioids** (e.g. heroin, methadone, dihydrocodeine, buprenorphine)
- **benzodiazepines** (e.g. diazepam & temazepam)
- **volatile substances** (e.g. 'gas' and 'glue')
- **other drugs** (such as cyclizine, ketamine, gammahydroxybutrate or 'GHB', 'poppers', steroids, anti-depressants).

Most women in Lothian who use drugs do not inject them. Oral **'polydrug'** use is more common. Cannabis is the most widely used illicit drug and is normally mixed with tobacco and smoked in a 'joint' or 'spliff'. Central nervous system (CNS) **stimulant drugs**, such as amphetamine, ecstasy and cocaine, are commonly used for 'recreational' purposes and are popular in the dance club social scene. **Anti-depressants** (mostly SSRI's) are also in widespread use. They are prescribed for the treatment of depression and

anxiety related problems and can interact with other CNS depressant drugs and CNS stimulant drugs.

Effects of commonly used drugs

Benzodiazepine drugs, such as diazepam (Valium®) and temazepam, are commonly called 'minor tranquillisers' or 'sleeping tablets' (hypnotics) and are CNS depressant drugs. They are easily available on the black market and are in widespread use. People can become dependent on benzodiazepines in a very short period of time if they are used continuously (ISDD 1999). Sudden withdrawal from benzodiazepines can result in severe anxiety symptoms, hallucinations and seizures (similar to alcohol dependency withdrawal symptoms).

Opioid drugs are CNS depressant drugs that have an analgesic ('pain killer') effect. They include:

- opiates… derived from the opium poppy e.g. morphine and codeine, and their
- synthetic analogues… e.g. methadone ('meth'), diamorphine ('heroin'), dihydrocodeine (DF118 or 'difs'), dipipanone (Diconal®), pethidine.

Opioids produce a range of physical effects apart from analgesia. They depress nervous system activity, including reflex functions such as coughing, respiration and heart rate. They also depress bowel activity, resulting in constipation. At higher doses sedation results and the user becomes drowsy and contented. Excessive doses produce stupor and coma. Tolerance and physical dependence develops with regular continued use. The physiological effects of long-term opiate use are rarely serious in themselves. They include respiratory complaints, constipation and menstrual irregularity (ISDD 1999).

Opioid intoxication… 'gouching' is the colloquial term used in Lothian to describe being intoxicated or 'stoned' on opiate drugs (i.e. the person takes a dose which is above their tolerance level). An intoxicated person may be unresponsive, have pinpoint pupils, respiratory depression (shallow and infrequent breathing), a weak and rapid pulse, and they may appear pale and have cold extremities.

Opioid overdose… is life threatening. Immediate medical attention and treatment is required (normally *naloxone* is administered to reverse the effects of overdose). A person who has taken an overdose will have blue lips and cold skin, will lose consciousness and not respond to stimuli, develop respiratory failure and die (sometimes through asphyxia after vomiting).

Opioid withdrawal in adults… abrupt withdrawal is rarely life-threatening and is considered less dangerous than withdrawal from alcohol or benzodiazepines. Withdrawal symptoms develop in dependent opiate users normally 24-72 hours after their last dose. Symptoms can include: nausea, vomiting, diarrhoea, insomnia, muscle cramps, goose flesh, cold and clammy skin, dilated pupils, runny nose and eyes, abdominal pains, sweating, restlessness, irritability, as well as intense craving for the drug. Physical symptoms normally subside without treatment within 7 days. For opiate detoxification during pregnancy see section on '*Management of problem drug use*', page 57.

Injecting drug use

Although most drug users in Lothian report taking drugs by oral administration (swallowing, snorting or smoking), *injecting drug use* is on the increase. Drugs that can be easily prepared for injection include:

- diamorphine ('heroin')
- buprenorphine (Temgesic®, Subutex®)
- dipipanone (Diconal®)
- cyclizine (Valoid®)
- amphetamines ('speed')
- cocaine.

Injecting drug use and **sharing** needles & syringes and other injecting paraphernalia (e.g. spoons, filters, water etc) remains a major public health concern. Messages about the risks associated with *sharing* injecting paraphernalia need to be continually emphasised by professionals as many young drug users do not perceive themselves to be at risk of ***blood borne viruses*** (HIV, hepatitis C and hepatitis B).

Drugs and their effects on the developing baby

Drugs and their effects on the developing baby

All women should be given information on the effects of smoking, alcohol use and drug use in pregnancy. Ideally, information should be given well before *conception* so that the woman has an opportunity to modify her drug use *before* she becomes pregnant (see section on '*pre-conceptual care*' page 65).

The general answer to a question like 'I took some x before I found out I was pregnant. Is it likely to harm the baby?' is almost certainly 'no'. However, outcomes depend on the drug used, the amount taken, over what time period, how it was taken, at what stage in pregnancy, and many other factors such as diet and social circumstances. One unfortunate aspect of over-emphasising the likelihood of adverse effects is that it may persuade some concerned women to inappropriately consider termination (Mounteney 1999). Others may suddenly stop their dependent drug use (which could be dangerous to the fetus) or avoid engaging with professionals because of exaggerated concerns.

Drug use is associated with increased rates of obstetric and paediatric *mortality* and *morbidity* and can affect pregnancy in a number of ways. During the 1st trimester, when fetal organs are actually forming, *teratogenic* (malformation) effects are the main concern. This is a time when the woman may not even know she is pregnant. During the 2nd and 3rd trimester the main concern is about *growth and functional* development (Siney 1999). Impaired placental function and fetal growth can result in a *low birth weight* baby. Chaotic drug use can increase the risk of *pre-term labour* and result in early delivery. The risk of *Sudden Infant Death Syndrome (SIDS)* is increased and *Neonatal Abstinence Syndrome* is common in the babies of women who are dependent on certain drugs.

Many women with alcohol / drug related problems feel *worried* and *guilty* about the effects of their drug use on the baby and may *appear* reluctant to discuss these issues as a result (Klee, Jackson & Lewis 2002). Professionals need to give parents license to voice concerns, fears and questions that they are reluctant to bring up spontaneously. Very often parents will be relieved when a professional *raises the subject* and

encourages them to share their concerns. Allowing them to voice anxieties about poor outcome and their ambivalence about their current situation, including their substance use, treatment and so on can be therapeutic. Parents often complain that they are not 'told enough' and professionals comment that parents are 'ill prepared' or 'ill informed'.

In Lothian, an **information booklet** called '***Pregnant… and using alcohol or drugs?***' is available (see *appendix 11*). This can be given to any woman with a drug and/or alcohol related problem in the antenatal period. The booklet is 'user friendly', outlining the general effects associated with drug use and advice about how to manage drug use during pregnancy. Women (and their partners) should be advised to read the booklet then discuss it with their midwife or other professional involved in their care.

Evidence base

It has been difficult to establish clear and reliable information about the effects of specific drugs on the developing fetus and baby. Much of the research is *methodologically flawed* and findings are inconsistent and contradictory. This is because well controlled studies are difficult to conduct and *pregnancy outcome is multifactorial*. It is the result of an interplay of genetic factors, physical and psychological health, nutrition, health and social care, social deprivation and other environmental influences as well as the effects of tobacco, alcohol and drug use. These *confounding factors* have made it difficult to establish *cause-and-effect* relationships. This is particularly true when relating specific intrauterine fetal drug exposure to long-term behavioural effects as the child grows up (Johnstone 1998).

Drug and alcohol related problems are associated with poverty, unemployment, chaotic lifestyle, violence, poor physical and psychological health and poor uptake of health and social care. These other factors may therefore account for many of the findings reported in the research literature. There is also a moral dimension to what purports to be objective scientific evidence (Mounteney 1999). Reports of adverse effects are more likely to be published than research reporting no adverse effects, irrespective of the scientific validity of the research (Koren et al 1989). The following information on *specific* drug effects should be read with these *limitations* in mind.

Effects of tobacco

The significant risks associated with maternal use of tobacco are particularly well established. There are many harmful substances contained in cigarettes. Nicotine, carbon monoxide and cyanide are thought to have the greatest adverse effects, reducing blood flow and oxygen to the fetus.

Maternal smoking in the first 12 weeks of pregnancy (until the end of the 1st trimester) is responsible for up to 25% of all *low birth weight* babies (Scottish Executive 2001). Smoking tobacco causes a reduction in birth weight *greater* than that from heroin and is a major risk factor in *Sudden Infant Death Syndrome* (Scottish Executive 2003).

Although there is no convincing evidence that smoking cigarettes causes congenital birth defects, many other pregnancy complications are associated with smoking (Johnstone 1998). These include:

- miscarriage
- pre-term (premature) delivery
- stillbirth
- intrauterine growth restriction (IUGR) or 'small for dates'
- low birth weight
- placental abruption
- reduction in breast milk production
- Sudden Infant Death Syndrome (SIDS or 'cot death').

Babies born to heavy smokers may also exhibit minor signs of withdrawal, including 'jitteriness' in the perinatal period (Scottish Executive 2003). Children of smokers also suffer more respiratory infections in childhood and adolescence.

Effects of alcohol

Alcohol use during pregnancy may potentially affect fetal brain development at any gestation. At all points along the continuum from occasional light drinking to regular heavy drinking there is conflicting evidence as to the possibility of damaging effects on the fetus (Mounteney 1999). **It is important to remember that a 'safe' level of alcohol use in pregnancy has not been established**.

Low levels (<7 units per week) of alcohol use during pregnancy appear to cause little harm for the baby, although in the 1st trimester it has been associated with an increased risk of *miscarriage* (Taylor 2003).

Maternal consumption of 15 units or more per week has been associated with a reduction in *birth weight*.

Consumption of 20 units or more per week has been associated with *intellectual impairment* in children.

Very heavy drinking in pregnancy (including heavy 'binge' drinking) results in a small number of babies being born with *Fetal Alcohol Syndrome* (FAS). In Scotland, there are an estimated 38 babies born per year with FAS.

Fetal Alcohol Syndrome is characterised by:

- Fetal *growth restriction* (with subsequent *low birth weight*, reduced head circumference and brain size)
- *Central nervous system problems*, including cognitive dysfunction (learning difficulties) and neurological abnormalities
- A cluster of characteristic *facial abnormalities* e.g. short palpebral fissures (eye openings), thin upper lip, flattened midface and indistinct philtrum
- *Failure to thrive* (the child remains below the 10th centile)

Studies that report alcohol consumption related to FAS have found high levels of drinking (>42 units per week). *Patterns of consumption* also seem to be important. Frequent high dose ('binge') drinking, to the point of intoxication, is thought to be a greater risk to the fetus than steady moderate drinking. Many other *confounding factors* however, may be important. These include general physical health, nutrition, age, parity, smoking and other drug use as well as social deprivation (Plant 1997, Abel 1998).

A wide range of other alcohol-related birth defects (ARBD) appear to occur with heavy drinking. These '*fetal alcohol effects*' include more subtle problems identified on behavioural, cognitive, psychological and educational tests.

Effects of drugs (illicit and prescribed)

As stated earlier, studies examining the effects of drugs in pregnancy are fraught with methodological difficulties and multiple confounding variables producing inconsistent and contradictory findings.

Drug effects on the fetus are *broadly similar* and largely *non-specific*. Intrauterine growth restriction (IUGR) and pre-term deliveries contribute to increased rates of low birth weight and increased perinatal mortality rate. These outcomes are *multi-factorial* and are also associated with socioeconomic deprivation, poor maternal health and smoking (Department of Health 1999).

Cannabis (e.g. marijuana or 'hash')
Despite its widespread use, information on the effects of cannabis in pregnancy is generally poor. A review of cannabis by the World Health Organisation (1997) concluded that there was no good evidence that cannabis itself has a direct effect on pregnancy or the developing baby. Cannabis however, is normally mixed together with tobacco and smoked in a 'joint'. Tobacco causes a reduction in birth weight, increased risk of sudden infant death syndrome (SIDS or 'cot death') and many other pregnancy complications (see page 37).

Benzodiazepines (e.g. diazepam & temazepam)
There is no conclusive evidence that benzodiazepine use by the mother causes adverse effects on the developing fetus. Most studies however, have studied low dose use, whereas many drug users in Lothian report high dose intake. There have been some reports of facial abnormalities (i.e. cleft lip and palate) following prolonged high dose benzodiazepine use in early pregnancy but these findings have not been reliably reproduced (Johnstone 1998). Benzodiazepines are associated with *withdrawal symptoms* in the newborn baby that can be severe and prolonged (see section on NAS, page 43). Because of concerns about the possible increased risk of cleft palate, reduced growth and brain development and long-term outcomes for the baby, dependent women are normally advised to *gradually reduce* their benzodiazepine use during pregnancy.

Opioids (e.g. heroin, methadone, dihydrocodeine)
Evidence on the effects of opioids is fairly limited, particularly on the long-term effects on the child. Opioids are associated with an increased risk of:

- *low birth weight*
- intrauterine growth restriction (IUGR) or '*small for dates*'
- *pre-term delivery* (associated with fetal withdrawal in-utero, poor diet and maternal health)
- *Sudden Infant Death Syndrome* ('SIDS' or 'cot death').

There is no convincing evidence that opioids cause any significant or permanent neurological damage or increased risk of congenital abnormalities (Johnstone 1998).

Abrupt withdrawal of opiates (i.e. 'cold turkey') has been associated with *miscarriage* in the 1st trimester and *stillbirth* and *pre-term labour* in the 3rd trimester (Department of Health 1999). Sudden opiate withdrawal is therefore considered potentially dangerous to the fetus, although the risks of withdrawal have probably been exaggerated in the past and can be minimised by appropriate drug therapy for the mother (Johnstone 1998). Most studies that report these findings relate to women with a history of *injecting* opiate use (primarily 'heroin') and chaotic *illicit* drug use. See section on '*Management of problem drug use*' for further information on drug reduction and detoxification during pregnancy (page 57).

Neonatal Abstinence Syndrome (NAS or 'neonatal withdrawal') is well documented in babies born to opiate dependent women and is the most commonly reported effect of opiate use in pregnancy. For more information see section on NAS, page 43.

Cocaine and 'Crack'
Cocaine is a powerful vasoconstrictor (restricting blood flow and oxygen to the fetus) and this effect is reported to increase the risk of:

- *placental abruption* (placental separation with haemorrhage and fetal hypoxia)
- *intrauterine growth restriction* (including reduced brain growth)
- underdevelopment of organs and/or limbs

- *fetal death in-utero* (miscarriage and stillbirth)
- *low birth weight* babies
- *pre-term* (premature) delivery.

Adverse effects have been largely reported in heavy crack/cocaine users, rather than with 'recreational' or occasional users. Cocaine 'binges' can potentially cause fetal brain infarcts due to sudden reduced blood flow (Ford & Hepburn 1997). **Mothers-to-be should be advised not to use cocaine or 'crack' in pregnancy if they possibly can.**

High dose cocaine use in the mother can result in the newborn showing *signs of intoxication* at birth that include: 'jitteriness', irritability, hypertonia, poor feeding and an abnormal sleep pattern. Neonatal Abstinence Syndrome (NAS) has not been reliably reported (Scottish Executive 2003).

Dependent crack/cocaine users should be managed by the consultant obstetrician and referred to a specialist drug agency for help (see *'services'* list).

Amphetamines (e.g. 'speed' or 'whizz')
There is no conclusive evidence that amphetamine use directly affects pregnancy outcomes. However, amphetamine sulphate is a powerful CNS stimulant and heavy users tend to have poor health (due to poor nutrition, weight loss, anaemia and mental health problems). Like cocaine, amphetamines cause vasoconstriction and hypertension, which may result in fetal hypoxia.

Withdrawal symptoms in the newborn baby have not been reliably reported with amphetamine use. As with other drugs, in the absence of good data, advice should be to avoid or at least reduce intake during pregnancy (Johnstone 1998).

Ecstasy ('E')
There is no conclusive evidence that ecstasy use directly affects pregnancy outcomes, however information in the literature is very scarce. Heavy users of ecstasy may have poor physical and mental health (e.g.

depression) and this may affect outcome. Ecstasy use by the mother does not appear to cause withdrawal symptoms in the newborn baby.

Hallucinogens
(e.g. LSD (lysergic acid diethylamide or 'acid') and 'Magic Mushrooms')
There is little evidence regarding the effects of hallucinogens in pregnancy. There is no evidence of congenital malformations and no conclusive evidence of other increased risks in pregnancy.

Solvents & volatile substances (e.g. 'glue' and butane gas)
There is little evidence regarding the effects of solvent and volatile substance use in pregnancy. However, inhaled solvents may reduce oxygen supply to the fetus and Neonatal Abstinence Syndrome has been reported in heavy users. A number of young people in Scotland die each year from the effects of volatile substances (usually as a result of arrhythmia) and women who continue to use volatile substances in pregnancy run the risk of sudden death (Johnstone 1998).

Neonatal Abstinence Syndrome (NAS)

Neonatal Abstinence Syndrome (NAS)

A group of drug withdrawal symptoms referred to as *Neonatal Abstinence Syndrome (NAS)* can occur in infants born to mothers dependent on certain drugs. NAS occurs because, at birth, the infant is cut off from the maternal drug supply to which it has been exposed *in utero*.

NAS is the most commonly reported adverse effect of dependent drug use in pregnancy. In Lothian, approximately 40 babies present with NAS each year and this number is likely to increase with the increasing prevalence of substance misuse.

The classes of drugs that are known to cause NAS include the opioids, benzodiazepines, alcohol, and barbiturates. Classical symptoms of NAS have not been consistently reported with solvents, hallucinogens, cannabis and most stimulants (Scottish Executive 2003). NAS symptoms are generally non-specific to the class of drug and differ from drug withdrawal symptoms seen in adults.

NAS is well described in babies born to *opiate dependent women*. The majority of infants born to dependent mothers (60-90%) will show varying symptoms of NAS.

Signs and symptoms of NAS

NAS is characterised by central nervous system irritability, gastro-intestinal dysfunction and autonomic hyperactivity.

The following signs and symptoms have been reported in **babies born to opiate and benzodiazepine dependent women** (including polydrug users) and describe the more *severe* range of symptoms that a baby may display:

- irritability (marked tremor, easily startled, increased reflexes and excessive crying)
- hyperactivity (excessive body movements, face scratching)
- hypertonicity (increased muscle tone and rigidity)
- a fairly continuous high-pitched cry
- inability to settle or sleep after feeds
- excessive sucking (including fist sucking)
- increased appetite

- poor feeding ability (hungry but difficulty in sucking, swallowing and successfully completing a feed)
- regurgitation and vomiting
- frequent loose stools or diarrhoea (which cause peri-anal excoriation)
- poor weight gain or weight loss
- repetitive sneezing, yawning, hiccoughs, nasal stuffiness
- tachypnoea (rapid shallow breathing)
- respiratory depression
- increased pulse and heart rate
- temperature instability, fever (>37.5 C), sweating and dehydration
- mottling (discolouration of skin)
- excoriation (skin abrasions) from excessive movement (usually seen around the buttocks, back of the head, shoulders, and heels)
- seizures (fits)

Seizures occur rarely (in approximately 5% of infants) and may manifest up to 30 days after birth (mean age of onset is 10 days).

The onset, duration and severity of NAS symptoms vary greatly and depend on many factors, including the:
- type of drugs used
- duration of mother's dependency
- timing and amount of the mother's last dose
- metabolism and elimination of the drug by the infant, as well as the
- gestational age of the infant.

Data on possible dose related effects of methadone are inconclusive (Johnstone 1998). Some studies show no correlation between maternal methadone dose and the development or severity of NAS. Others have found a weak positive correlation. Little data exists on the dose related effects of maternal benzodiazepine use.

Symptoms normally present within the first 24 - 72 hours of birth (in approximately 75% of cases). Methadone withdrawal in the neonate can present *later* than heroin withdrawal. Methadone withdrawal symptoms can also *last longer* and be *more severe* (Sparey & Wilkinshaw 1999). The onset of benzodiazepine withdrawal in neonates can also be delayed (due

to slow metabolism in the neonate) presenting at 5-10 days of age (Coghlan et al 1999).

Acute symptoms of NAS may persist for several weeks and irritability can last for some months (particularly from benzodiazepines). *Pharmacological* treatment is required for some infants with acute symptoms (approximately 25% - 40%). Most studies show that babies who require treatment develop symptoms within 72 hours of birth, including babies born to methadone dependent women (Shaw & McIvor 1994).

Withdrawal symptoms in **pre-term infants** tend to occur later than full-term infants and are generally milder and require less treatment (Doberczak et al 1991). This is thought to be due to a number of different factors, including: their reduced total drug exposure *in utero*, the developmental immaturity of their central nervous system, the different metabolism of pre-term infants, and reduced ability to communicate the distress of withdrawal.

Some babies may present with symptoms of NAS with *no reported history* of maternal drug use. If NAS is suspected then the neonatal paediatrician can confirm the diagnosis by toxicology and will discuss the results sensitively with the parents.

Assessment of NAS

Assessment of the infant is best done using a standardised tool or *formal assessment score chart* as this provides the *most* objective measure of symptoms and the best guide for making decisions about treatment and care (Shaw 1999).

In Lothian, assessment is normally carried out using either the '*Lipsitz tool*' or a modified version of the *Finnegan* chart (see *appendix 10*), where numerical values are allocated on the basis of the presence and severity of various symptoms. The main dimensions that are measured include *irritability* symptoms (high-pitched cry, sleep pattern, body movements etc) and *gastrointestinal* symptoms (feeding pattern, weight, skin excoriation etc). A score is allocated to each symptom for each time period (e.g. 9am - 1pm, 1pm – 5pm, etc). Total scores for each time period are then calculated and trends in the severity of the baby's condition are

monitored. Any drug treatment administered is also recorded on the chart. This allows the medical staff to monitor the effectiveness of the drug treatment and to titrate the dose according to the infant's presenting symptoms, weaning the baby off gradually.

Applying the NAS score chart to *pre-term* infants can cause difficulties as symptoms such as high pitched cry, poor feeding and tachypnoea could be *over scored*, whilst other symptoms such as sleep pattern, muscle tone and fever could be *underscored*. Pre-term infants are cared for in hospital so staff should seek advice from the neonatal paediatrician.

All maternity staff should make themselves familiar with the current NAS score chart in use and be able to explain its use to parents. Contact your *Link Midwife for Substance Misuse* for advice if in doubt (see list in *appendix 2*).

Preparing parents for NAS

It is important to prepare parents for the possibility that their baby might develop NAS (even if they are dependent on very low doses of medication) and to communicate this information to them sensitively, using a non-judgemental approach.

Parents who have an infant with NAS experience the same range of emotions as any other parent of a newborn baby who is poorly. Anxiety, helplessness, fear and grief are commonly reported feelings. In addition they often feel guilty and 'to blame' for their baby's condition and will require considerable support, reassurance and encouragement. Caring for a baby with NAS can be very stressful and parents will require a lot of patience. Involving the parents in all the decisions and choices about their infants care and keeping them fully informed of the baby's progress is important.

Ideally, parents will have been given clear and accurate information about NAS in the *antenatal* period so that they are well prepared. At around 32 weeks, midwives should give all drug and alcohol dependent parents the information leaflet '***Caring for a baby with drug withdrawal symptoms***' (see *appendix 12*). This leaflet outlines in 'user friendly' language, what parents can expect and how they can help. The woman and her partner

should be advised to read the leaflet then discuss any questions or anxieties that they may have with the midwife.

Management of neonatal withdrawal symptoms

The focus of care should be to:

- ✓ foster the maternal/infant bond
- ✓ ensure the safe adaptation of the baby to extra-uterine life
- ✓ detect any evidence of NAS symptoms and to offer appropriate treatment and care

Unnecessarily prolonged hospitalisation or placement away from the parents should be avoided if at all possible in an effort to keep mother and baby together, to enable effective breastfeeding and to promote good bonding (Scottish Executive 2003).

All known drug dependent women should be asked to stay in hospital for a minimum of three days (72 hours) following delivery so that the neonate can be observed for signs and symptoms of NAS. Most babies with *mild to moderate* symptoms will be cared for in the *postnatal* ward. Staff in the postnatal ward should show parents how to use the NAS assessment score chart (see *appendix 10*) and encourage them to get involved in their baby's care from the very beginning. Parents should be advised to keep a close eye on their baby and report any concerns to staff.

Babies with mild symptoms *will not* require medical intervention and can be looked after using supportive '*comfort*' measures.

Supportive 'comfort' measures include:

- ✓ Provide a supportive environment (ensure minimal stimulation to the infant by decreasing stimuli in a quiet room with dim lighting, mild temperature, soft gentle music, no smoking near baby). If appropriate the mother should be offered a single room in hospital so that a suitable environment can be created for the baby.
- ✓ Recommend 'skin-to-skin' contact with mother to help regulate the baby's breathing and body temperature, relaxation and feeding. The mother should be asked to read the 'skin-to-skin' leaflet.

- ✓ Swaddling of the baby will help with tremors, jerks and restlessness. When handling, wrap limbs (with arms and knees bent into a comfortable position) with a light soft flannel blanket, perhaps use a cotton baby sling.
- ✓ Ensure gentle handling of the baby, gentle wakening, gentle rocking, humming, perhaps try gentle baby massage and deep relaxation bath. Before disturbing the baby for changing, prepare everything that is needed.
- ✓ Provide a dummy or pacifier for non-nutritive sucking (except when breastfeeding). Cover the infant's hands with mittens to prevent trauma to fingers and fists.
- ✓ Ensure frequent changes of the baby's nappy. Use barrier creams to the skin around buttocks to prevent skin damage from frequent loose stools and excessive body movements.
- ✓ Feed the infant on demand, small frequent feeds are normally better and will reduce regurgitation and vomiting and prevent dehydration. Burp the infant frequently as infants often swallow air due to their uncoordinated and poor sucking reflex.
- ✓ If the baby's sucking and swallowing reflex is poor then support the cheeks and lower jaw to enhance feeding.
- ✓ If the baby is being breast fed, feed in quiet, calm surroundings with minimal noise and disturbance and allow time for resting in-between sucking.
- ✓ Observe baby's temperature and remove blankets if fever is present. Clean skin and change clothes frequently if baby is sweating.

The use of supportive therapy has been shown to reduce the effects of withdrawal in neonates and should be implemented as soon as possible following birth. Parents should be encouraged to take a lead role in their infants care and should be provided with this information so that they can care for their baby appropriately.

Please note: ***naloxone*** (an opiate antagonist) **should not be used** to reverse opioid induced respiratory depression in neonates as this will induce an abrupt opiate withdrawal crisis.

Care in the community

After 72 hours stay on the postnatal ward, babies with mild to moderate symptoms can be discharged home where they can be cared for by their *parents* with community midwifery and health visiting support. The midwife will offer advice and support on a daily basis and will arrange for readmission to hospital if the baby's symptoms worsen. As part of the infant's ongoing care, parents should be advised to continue using the NAS assessment score chart and supportive therapy measures until the baby's symptoms have resolved. Parents should be advised to *record* all feeds (amounts taken and times) so that the midwife and health visitor can monitor the baby's daily calorie intake. The community midwife and health visitor will also *weigh* the baby to ensure weight gain is satisfactory.

If the baby's symptoms get significantly worse at home (i.e. sleeps less than 1 hour/ cries 1 hour after feeds/ weight loss after day 7) then it is better to admit the baby to hospital *earlier* rather than later. If the baby has been home for less than a week, or is less than 10 days old they may be admitted to the *Neonatal Unit* at RIE, Little France or *Special Care Baby Unit (SCBU)* at St John's Hospital, West Lothian. If the baby is *more* than 10 days old they are likely to be admitted to Sick Children's Hospital (RHSC) or the Children's Ward at St John's Hospital. Community staff should discuss admission with the Neonatal Unit / SCBU first.

Care in hospital

Parents need to know that admission to the *Neonatal Unit* at Little France or the *SCBU* at St John's Hospital is necessary if their baby develops *severe* withdrawal symptoms.

Babies with severe symptoms often require 'tube' feeding, pharmacological (drug) treatment and 24-hour care and supervision from specialist paediatric medical and nursing staff.

The *aim* of treatment is to:

- ✓ reduce irritability and motor instability
- ✓ establish an appropriate *feed/sleep/wake* cycle
- ✓ maintain a normal body temperature, and
- ✓ ensure adequate weight gain.

Babies with severe symptoms usually stay in the unit for about 10-14 days, but sometimes for much longer. Mothers are encouraged to 'board' (rooms permitting) in the hospital whilst their baby is in the unit (particularly if they are breastfeeding) or at least have daily contact to continue the bonding process.

In Lothian, pharmacological management is decided by the attending physician but normally includes the use of one or more of the following drugs: oral morphine, diazepam, clonazepam, clonidine, phenobarbitone, chlorpromazine or chloral hydrate. The best drug appears to be morphine if the main drug used by the mother has been an opioid. Where other drugs (e.g. benzodiazepines) have been used alone or in combination, drug therapy needs to be individually tailored towards a longer or biphasic pattern of withdrawal (Shaw 1999). Care is taken not to sedate the baby and to wean them off medication as soon as possible. Babies can be discharged home as soon as they are well enough to be cared for by their parents.

Management of substance use

Management of substance use in pregnancy

Many women who are not truly dependent on alcohol or drugs will stop spontaneously as soon as they know they are pregnant. This applies to approximately 20% of women who smoke and to many women who use cannabis and other drugs 'recreationally'. It also applies to some 'controlled' opiate and benzodiazepine users (Johnstone 1998). For most drug use (excluding opiates) the immediate goal would be one of abstinence, although in reality this may be difficult to achieve for many women. Much support and drug counselling may need to be offered to help the woman work towards this goal.

In addition, research shows that women who have substance misuse problems are more likely to have **substance-misusing partners** (Effective Interventions Unit 2002). Substance-misusing sexual partners can exert a powerful influence over a woman's drug use. It is very important therefore, to include the woman's partner (where appropriate) in any treatment and care plan so that the most supportive environment can be created. Evidence suggests that women, who engage in treatment *with*, rather than without, their partner, have better outcomes (Effective Interventions Unit 2002).

Smoking cessation

All women should be advised to stop smoking or given help to cut down, preferably *before* they conceive. General Practitioners can prescribe nicotine replacement therapy (NRT) and can refer to smoking cessation programmes. Bupropion (Zyban®) can also help with nicotine cravings, however women who are pregnant or breastfeeding should not use bupropion (NICE 2002).

During pregnancy a **pro-active approach** to smoking cessation is required. Smoking cessation advice given in the antenatal period has been shown to be effective and can result in significant gains in birth weight (Johnstone 1998).

Many drug and alcohol dependent women however, may find it difficult to stop smoking. Pregnant women who are strongly nicotine dependent and unable to quit unaided, can be offered nicotine replacement therapy (NRT)

following discussion with a health care professional or as part of the '*Want 2 Quit*' programme, which includes an assessment of motivation, counselling and support. Although NRT is not licensed for use during pregnancy, a number of leading experts have put forward a rationale for treating pregnant smokers with NRT (Wright & Walker 2001). The use of NRT can benefit the mother and fetus if it leads to cessation of smoking. Nicotine levels in the body whilst on NRT are typically lower than those present during heavy smoking and the many other toxins emitted by cigarette smoke, such as carbon monoxide are avoided.

Many areas throughout Lothian now have smoking cessation support groups and practitioners who have a specific remit for smoking cessation. Contact the local GP surgery, local pharmacy, Health Visiting or Midwifery service for further information. Information leaflets on smoking cessation are available for women and their partners and can be given out during pre-conceptual and antenatal consultations (available from NHS Health Scotland). The National Institute for Clinical Excellence (NICE) also has guidance on NRT in their '*Information for Patients*' leaflet (www.nice.org.uk).

It is easy to forget the risks associated with smoking in pregnancy when working with women who are using a whole variety of other drugs. Many women themselves are more concerned about the effects of other drugs, especially opiates. Professionals need to remind themselves that providing information on the risks of smoking is important if they are to convey a balanced and consistent message on the subject.

Advice on alcohol consumption

'*Safe' levels* of alcohol use in pregnancy have yet to be precisely established, so ideally women should abstain from alcohol during pregnancy. Alcohol differs from other drugs in that it is generally considered socially acceptable to drink occasionally. If a pregnant woman chooses not to drink during her pregnancy then she should be encouraged for this decision and not pressured to drink.

The Royal College of Obstetricians and Gynaecologists (RCOG) recommend that pregnant women be advised not to drink more than *one unit of alcohol per day* (Taylor 2003).

Scottish Executive advice recommends no more than '*1 to 2 units, once or twice a week*' (HEBS 2002). Pregnant women who are concerned about low levels of consumption can be reassured that one or two small drinks a day (i.e. <14 units per week) is unlikely to do any harm (Mounteney 1999).

Please note:
One '*unit*' of alcohol is the equivalent to:
- ✓ half a pint of 3.5% beer,
- ✓ one 25ml measure of spirits,

One small (125ml) glass of average strength (12%) wine contains 1.5 units.

See SIGN guidelines '*The Management of Harmful Drinking and Alcohol Dependence in Primary Care*', Annex 1 (2003) www.sign.ac.uk for more detailed information on alcohol unit measures.

Remember that home measures are often much larger than pub measures. 'Sensible drinking' for women who are *not pregnant* is defined as not consuming more than 3 units in any day (i.e. no more than 21 units per week), and avoiding any heavy 'binge' drinking, defined as consuming double the recommended daily amount on one occasion i.e. 6 units or more for women (Scottish Executive 2002).

Antenatal screening for problem drinking

It is important that information on alcohol consumption is integrated into routine history taking in antenatal care. Routine antenatal care provides a useful opportunity to *screen* for hazardous levels of drinking and to deliver *brief interventions* for reducing alcohol consumption (Chang et al 1999). Pregnant women in Lothian are routinely asked about their alcohol consumption at the '*booking appointment*' when they see the midwife, but little follow-up questioning occurs (McIntosh 2001). **Alcohol use, especially at the level of harmful use, often goes undetected.** Women who drink heavily before conception are more likely to continue drinking heavily during pregnancy without intervention and concurrent drug and alcohol use is associated with poorer outcomes (Robertson 1998). It is important that these women are identified early in pregnancy and are offered help.

There is good evidence that *screening questionnaires* (such as TWEAK, T-ACE or shortened versions of AUDIT) can improve detection of problem drinking in pregnancy and are easy and quick to administer in antenatal and obstetric settings (Bradley et al 1998). The Royal College of Obstetricians and Gynaecologists (RCOG) recommends the 'T-ACE' screening test as the most effective way of detecting harmful levels of alcohol consumption in pregnancy (Taylor 2003). **Routine antenatal screening, using the T-ACE screening test is therefore recommended in Lothian** *(see appendix 7).* This simple four-question test that takes about one minute to ask will correctly identify the majority (approximately 70%) of hazardous drinkers during pregnancy. The **T-ACE** questions are listed below.

T (tolerance) How many drinks does it take to make you feel high?
Answer: '*3 or more drinks*' scores 2 points

A (annoyance) Have people annoyed you by criticising your drinking?
Answer: '*Yes*' scores 1 point

C (cut down) Have you ever felt you ought to cut down your drinking?
Answer: '*Yes*' scores 1 point

E (eye-opener) Have you ever had a drink first thing in the morning to steady your nerves or to get rid of a hangover?
Answer: '*Yes*' scores 1 point

A total score of greater than or equal to *two points* is considered positive.

Management of problem alcohol use

Most women will cut down their alcohol consumption when they find out they are pregnant or when they are given advice to do so. *Brief interventions, harm reduction advice, motivational interviewing* and *relapse prevention techniques* are effective methods of reducing low to moderate levels of drinking. For further information on these interventions see www.alcoholconcern.org.uk, refer to '*The Management of Harmful Drinking and Alcohol Dependence in Primary Care*' (SIGN guideline 2003) and '*Brief Interventions*' factsheet (Alcohol Concern 1997).

If a '**hazardous' drinking score** is obtained using the T-ACE test then professionals should consider offering the woman one or more of the following interventions:

- ✓ Give the woman clear advice to cut down her alcohol consumption; refer her to page 8 of the '*Ready Steady Baby'* book
- ✓ Ensure the woman is educated about the increased risks associated with moderate to high levels of drinking in pregnancy
- ✓ Give the woman the self-help booklet '*So you want to cut down your drinking?*' (HEBS 1998)
- ✓ Complete a '*drink diary'* (see *appendix 8*) by asking the woman to detail what she had to drink on each of the previous seven days
- ✓ Ask the woman to describe in more detail her pattern of drinking and alcohol consumption *before* conception and *since* conception
- ✓ Discuss your concerns with the woman's midwife, consultant obstetrician, GP or other 'key worker' (preferably with the client's consent)
- ✓ Arrange an appointment for the woman to see the consultant obstetrician or GP
- ✓ Consider referral to an *alcohol service* for specialist assessment and advice (gently broach this subject with her and obtain consent before referral)

Alcohol detoxification

Dependent alcohol use is such a serious risk to the fetus that *detoxification* should be considered at any gestation. Tolerance to alcohol normally develops at high levels of consumption; however tolerance may develop at lower levels of consumption in some women using multiple drugs. Sudden cessation of heavy drinking is potentially dangerous to the mother (because of seizures) and may cause fetal distress. Alcohol dependent pregnant women should be advised *not* to suddenly stop drinking but to consult their GP as soon as possible. Alcohol detoxification requires close monitoring of mother and fetus under specialist medical supervision that includes collaboration with an obstetrician and alcohol specialist and is normally conducted in an inpatient setting (Plant 2001). Since the effects of alcohol are associated with dietary deficiencies, the importance of a balanced diet and vitamin supplementation should be discussed. Liver function tests, including prothrombin time should be measured. Disulfiram (*Antabuse®*) is *contraindicated* for women who are pregnant or

breastfeeding because of the risk of teratogenic effects. Women who conceive whilst taking this drug should receive counselling before deciding to continue with the pregnancy (Plant 2001).

Those women who report that they are *unable* to reduce high levels of consumption should be referred to the **Alcohol Problems Service (APS)** at the Royal Edinburgh Hospital for specialist assessment and help (see '*services list*' for details). Pregnant women who are drinking heavily are seen as a *high priority* for the APS. Any referral will be dealt with promptly and the woman would be offered in-patient and/or out-patient care depending on her circumstances. Referrals should be made in writing. Any professional can refer and a quick assessment can be offered. Alternatively, contact your local *APS Community Mental Health Nurse* for advice and information.

Women who are in-patients or attending out-patients in the ***hospital setting*** can be referred to the **Department of Psychological Medicine** based at the Royal Infirmary. Two specialist *alcohol liaison nurses* work as part of this team and can offer assessment and advice. In West Lothian, a member of the liaison psychiatry team will see in-patients in St John's Hospital (see '*services list*' for details). Other specialist alcohol services are included in the *services list*.

Please note: Alcohol detoxification should be discussed and agreed with the woman's consultant obstetrician and alcohol specialist beforehand and should be part of a package of care that includes relapse prevention (see section '*Risk of relapse*', page 92).

Assessing drug related problems

It is important to establish an accurate picture of a woman's drug use during pregnancy so that appropriate interventions and care can be offered.

An **assessment of drug use** during pregnancy may include such things as:

- ✓ taking a detailed history of the woman's drug use
- ✓ asking the woman to complete a '*drug diary*' (see *appendix 8*)
- ✓ assessing drug-related harm (e.g. the physical, psychological, social, legal, financial, lifestyle consequences of the woman's drug use)
- ✓ assessing the woman's aspirations and *motivation to change*
- ✓ *toxicology* (to screen for recent drug use)
- ✓ assessment of *withdrawal* symptoms
- ✓ *tolerance testing* or supervised self-administration of methadone.

Professionals who are involved in the assessment or care of a woman with a drug related problem should:

- ✓ Discuss the woman's care with her General Practitioner or other prescriber
- ✓ Refer the woman to an appropriate drug service if she is not already attending one so that an assessment can be made
- ✓ Seek advice from the woman's drug treatment specialist.

Management of problem drug use

The **key aim** of professionals should be to attract women into health and social care treatment services, provide antenatal care and stabilise or reduce drug use to the lowest possible dose (Department of Health 1999).

Much of the skill in drug management lies in planning **realistic and achievable goals** with each individual woman. Professionals need to be careful not to force their own ideals or 'agenda' on the woman. Many women already feel *guilty* and *worried* about the effects their drug use may be having on their unborn child. If women feel they are not meeting the perceived expectations of professionals they may under-report their drug use and conceal any difficulties they may be experiencing. Trying to persuade a woman to reduce or stop using drugs may simply alienate her, lead to relapse and a sense of failure and result in non-attendance. Different treatment options need to be considered in the light of the

woman's aspirations and particular social and psychological circumstances. Drug use may have been an integral part of the woman's lifestyle for many years and she may have no intention of changing this. She may have had a previous pregnancy whilst using drugs with no apparent ill effects. This may be reinforced by drug-using friends who have also successfully delivered healthy babies (Johnstone 1998).

Different **drug treatment options** to consider include:

- ✓ Safer drug use advice and education
- ✓ Needle exchange and safer injecting advice
- ✓ Substitute prescribing
- ✓ Stabilisation
- ✓ Slow reduction
- ✓ Detoxification

Safer drug use

Injecting and *chaotic drug use* in pregnancy is associated with increased risks for both mother and baby. These risks include:

- sudden death through drug *overdose*
- transmission of *blood borne viruses* (including HIV, hepatitis C and hepatitis B)
- other complications associated with poor injecting practices and the contaminants contained in non-pharmaceutically prepared street drugs
- pre-term labour and delivery
- multiple social problems

Reducing illicit, chaotic and injecting drug use in pregnancy is therefore an important goal to work towards.

Pregnant women who are injecting drugs can be referred to the *Harm Reduction Team* (HRT) at Spittal Street Centre for supplies of clean injecting equipment, specialist advice about safer injecting practices and the 'low threshold' methadone programme. Free supplies of clean needles & syringes can be obtained from many pharmacies throughout Lothian. Contact the HRT (Tele 0131 537 8300) for a list of pharmacies who participate in the needle exchange scheme. Alternatively, refer women to your local voluntary sector drug agency as most provide needle & syringe exchange services as well as harm reduction advice. See '*services list*'.

Substitute prescribing

Lothian has a longstanding history of community based drug services, which provide a range of treatment and care approaches. Many people with a drug dependency in Lothian are prescribed substitute drugs for the treatment of opioid and benzodiazepine dependence (approximately 3000). Many attend their General Practitioner and other specialist drug services. Pregnant women drug users are seen as high priority for the *Community Drug Problem Service (CDPS)* and most other drug services in Lothian.

Lothian's policy and guidelines on prescribing drugs for the treatment of drug dependence are outlined in a handbook entitled '*Managing Drug Users in General Practice'* (Lothian Primary Care NHS Trust, 4th Edition 2003). The Primary Care Facilitator Team (HIV/Drugs) oversees the '*Scheme for supporting the care of drug users in general practice'* and regularly visits participating Primary Care Teams to discuss policy and practice. For further information refer to the handbook.

Methadone maintenance for **opioid dependence** is recommended by the Department of Health (1999) and is the most generally accepted treatment for opiate dependent pregnant women (Kandall et al 1999). Methadone is normally taken orally in liquid form (methadone mixture 1mg/1ml). It is used to help people *stabilise* their drug intake and associated lifestyle. Because methadone mixture is *long-acting* it offers stability of drug levels for both mother and fetus.

There is *strong research evidence* (Department of Health 1999) for the benefits of **methadone maintenance** treatment when given consistently, in adequate dosage, with adequate supervision and in the context of psychosocial support. Five identified benefits according to the research literature (Ward et al 1998) include the:

- ✓ reduction of injecting behaviour
- ✓ reduction of the risk of viral transmission (HIV, hepatitis B & C)
- ✓ reduction of drug related deaths
- ✓ reduction of illicit drug use
- ✓ reduction of offending behaviour

Follow-up studies suggest the long-term outcome in women who enter methadone treatment programmes during pregnancy is better in terms of

their pregnancy, childbirth and infant development, irrespective of continued illicit drug use (Department of Health 1999). Women attending treatment services usually have *better antenatal care* and *better general health* than drug-using women *not* in treatment, even if they are still using illicit drugs on top of their substitute prescription.

Dihydrocodeine (DF118) is another opiate drug that is prescribed in Lothian and is currently being researched for its comparative effectiveness with methadone. Local guidelines (Lothian Primary Care NHS Trust 2003) recommend prescribing a maximum of 15 x 30mg tablets per day. Doses above this amount should only be exceeded in consultation with the Community Drug Problem Service (CDPS). The CDPS also prescribes **buprenorphine** (an opiate partial agonist) for supervised drug detoxification programmes and for maintenance prescribing. Both dihydrocodeine and buprenorphine have also been used as substitute drug therapy in pregnancy and there is some evidence to suggest that babies born to these mothers may be at lower risk of Neonatal Abstinence Syndrome than with other opiates (Wright & Walker 2001).

Lothian also has a longstanding history of prescribing substitute drug treatment for **benzodiazepine dependency**. This treatment approach has changed in recent years due to lack of evidence for its effectiveness and concerns that long term benzodiazepine use may cause harm in the form of cognitive impairment and mood disturbance. Many drug users in Lothian however, continue to be prescribed diazepam (Valium®). The recommended *maximum* dose of diazepam is now 30mg per day. GP's are advised to reduce doses larger than this and *not* start any new drug user on prescribed benzodiazepines. Women who are prescribed benzodiazepines are normally advised to reduce to the lowest possible dose in pregnancy and should be prepared for the likelihood of *Neonatal Abstinence Syndrome* if they remain benzodiazepine dependent (see section on NAS, page 43).

Stabilisation

Pregnant women who are **opiate dependent** *should not* be required to make a commitment to reduce or come off their prescribed opiate drugs. The emphasis instead should be on support and engagement rather than enforced reduction or abstinence (Wright & Walker 2001). Stabilised

drug use should be the *first goal to work towards* and may take some time to achieve. The aim is to *minimise the risks* to mother and baby, not only during pregnancy and the neonatal period, but ideally in the long term. Stable drug use, a stable lifestyle and abstaining from illicit (street) drug use are successful outcomes of treatment.

If non-prescribed opiate use persists, the methadone dose may need to be increased in order to achieve stability and to help the woman abstain from street drug use (Department of Health 1999). However, the risk of overdose if other drugs are taken and the likelihood of *Neonatal Abstinence Syndrome* (NAS) need to be understood by the woman (see section on NAS, page 43).

Some studies show that plasma levels of methadone *decrease* with gestation (Johnstone 1998). This may be due to the increased fluid space and a large tissue reservoir as well as altered metabolism of the drug by the placenta and fetus. Lowering the dose to avoid complications may therefore be inappropriate and the woman may require an *increase* in methadone during gestation. Advising the woman to try dividing her daily dose can sometimes overcome the need for an increase (Department of Health 1999). Conversely, in the immediate postnatal period, a reversal of these effects may lead to *increased* methadone plasma levels with intoxication effects and the dose may need to be reduced. It is important to warn the woman about this effect as it may have implications for the care and safety of the baby.

Reduction

Slow reduction in pregnancy is also an option but should be gradual, stepwise and tailored to the woman's response. Generally the principle of incremental reductions in drug dosage to a level that minimises withdrawal in the fetus should be explored with the woman. If the woman is dependent on benzodiazepines as well as opiates, then she should be advised to try reducing her **benzodiazepines** first (Lothian Primary Care NHS Trust 2003). Diazepam (Valium®) is the drug of choice to prescribe, as it is longer acting than other benzodiazepines. **Diazepam** should be prescribed at *no more than* 30mg daily, reducing fortnightly-monthly in 2mg to 5mg decrements. **Methadone** can be reduced weekly or fortnightly in 2.5ml to 5ml decrements. **Dihydrocodeine** ('DF118') can also be

prescribed at *no more than* 30mg tablets x 15 per day, reducing one tablet per week for 15 weeks. Women who are on **buprenorphine** when they become pregnant should be referred to the CDPS for specialist drug management.

The woman's stability should be reassessed at each stage of the reduction before proceeding further. If the woman has not relapsed back into illicit drug use (this may be confirmed through toxicology) and wishes to continue the reduction, then proceed. If the reduction is commenced early in the 2nd trimester (i.e. 13 weeks) it may be possible to achieve dosages low enough at delivery to avoid significant withdrawal symptoms in the neonate (e.g. a dose less than 20mg of methadone or 150mg of dihydrocodeine). However, the woman needs to understand that this cannot be guaranteed and the parents should still be prepared for NAS (see section on NAS, page 43).

Detoxification

Detoxification from **opiate** drugs may be considered at any gestation, however it is normally recommended during the 2nd trimester (Department of Health 1999). Rapid detoxification should be avoided in late pregnancy (Johnstone 1998). In the 1st trimester it is associated with an increased risk of *miscarriage* and in the 3rd trimester it has been associated with *pre-term labour* (Department of Health 1999). Opiate detoxification is rarely fatal for the mother and less serious than withdrawal from benzodiazepines or alcohol, but can be very unpleasant.

Rapid **benzodiazepine** detoxification should be avoided as this can lead to withdrawal seizures (fits) in the mother and fetal distress (Department of Health 1999). Detoxification treatment should be similar to that of alcohol detoxification. Hospital or residential admission is necessary to supervise a gradual titrated detoxification and to monitor the fetus.

Detoxification should be discussed and agreed with the woman's consultant obstetrician and drug specialist / prescriber beforehand and should be part of a comprehensive package of care that includes relapse prevention (see section '*Risk of relapse*' page 92).

A final word:

Over the years, much emphasis has been placed on pregnancy being a '*catalyst for change*' or a '*window of opportunity*' for women to either stop using drugs or to reduce their drug use and many pregnant women will tell professionals that this is what they want to do. In Lothian, as in other areas throughout Britain, experience has shown that this has not generally proved to be the case. Many women who try to reduce or come off drugs during pregnancy are not successful. However, all attempts that pregnant women make to improve their health and social circumstances should be supported by professionals and be regarded as a successful outcome of care.

Maternity care

Maternity care

The next section of the resource pack provides information and *guidelines on good practice* for maternity care. Maternity care includes:

- pre-conceptual care
- antenatal care
- intrapartum care
- postnatal care/parenthood

Pre-conceptual care

Good health and social circumstances *before* pregnancy benefits the woman, her unborn baby and the wider family (Scottish Executive 2001). All professionals should routinely ask women whether they have any plans to have a child in the near future, or whether they may be currently pregnant (Scottish Executive 2003). This questioning needs to be done *sensitively* as part of the overall assessment and care planning process. Helping a woman prepare and plan for pregnancy and motherhood provides a good opportunity to offer healthy lifestyle and *harm reduction* education and advice.

All women with drug and alcohol related problems could benefit from receiving information and advice on:

- ✓ contraception
- ✓ sexual health
- ✓ reproductive health
- ✓ pre-conceptual care.

Reproductive health and drug use

Reliable information on how drug use affects women's reproductive health has been difficult to establish and findings are often inconclusive. Theoretically, illicit and dependent drug use can affect fertility in a number of ways (Ford & Hepburn 1997).

Substance misuse is associated with poor nutrition and loss of appetite. Significant weight loss can cause *amenorrhoea* (absent periods) with *anovulation* (failure to ovulate or produce eggs). Opiates (such as heroin, methadone & DF118) and stimulants (such as amphetamines, cocaine & ecstasy) can interfere with a woman's monthly cycle in this way.

Amenorrhoea *does not* necessarily mean that the woman is unable to conceive (fall pregnant) as she may still be ovulating, so effective contraception to avoid unwanted pregnancies is still required. Irregular or absent periods means that some women may not realise they are pregnant until late in pregnancy when fetal movements are felt, or until other changes are noticed.

Fertility may increase around the time when a woman reduces or comes off drugs or when she starts treatment with substitute drugs, such as methadone. Offering contraceptive advice and pre-conceptual counselling therefore needs to go hand in hand with the beginning of any drug treatment (Ford & Hepburn 1997).

All professionals can encourage women to attend health care services that provide *contraceptive* and *sexual health* advice and care. GPs and family planning clinics will discuss contraceptive options and advise women about how to get emergency contraception if needed.

Women with substance misuse problems may plan to conceive or may have an unplanned pregnancy. If pregnancy is planned then *pre-conceptual care* can be offered.

Pre-conceptual advice

Health, social and voluntary sector professionals all have a role to play in providing pre-conceptual care to women with substance misuse problems (Ford & Hepburn 1997). *General Practitioners* are in an ideal position to provide pre-conceptual care to drug-using women who are attending their medical practice for a substitute prescription. If the woman is attending the *Community Drug Problem Service (CDPS)* or *Harm Reduction Team (HRT)* for her prescription then specialist drug workers have an excellent opportunity to provide pre-conceptual care. Other workers can address many of the social issues and encourage women to attend to any health checks that they may need.

Pre-conceptual care may include a discussion on some or all of the following topics:

- ✓ Information on maternity services in Lothian and the importance of antenatal care
- ✓ The woman's past obstetric history, including past pregnancy outcomes and the health and social circumstances of previous children
- ✓ The importance of good nutrition and a healthy balanced diet
- ✓ The use of folic acid to prevent neural tube defects
- ✓ Checking for rubella immunity and vaccination if indicated
- ✓ Testing for sexually transmitted diseases if needed e.g. chlamydia
- ✓ Cervical smear if needed
- ✓ Screening for toxoplasmosis and cytomegalovirus (if HIV positive or immunosuppressed)
- ✓ The importance of good oral hygiene and dental care
- ✓ The benefits of breastfeeding
- ✓ Immunisation for hepatitis B, and possibly hepatitis A
- ✓ Healthy lifestyle education, including physical exercise, reducing stress etc
- ✓ The importance of post-natal contraception and preventing unwanted pregnancies
- ✓ Assessment of other physical and psychological health problems that may affect pregnancy and parenthood i.e. significant illnesses, domestic abuse, past or present mental health problems etc
- ✓ Assessment of social circumstances, including such issues as housing, debts and welfare benefits, employment and training, offending behaviour and legal circumstances etc
- ✓ Assessment of support networks, including partners, parents, other family members and friends
- ✓ The partner's history of drug / alcohol related problems, including their current use and level of stability if drug dependent
- ✓ Advice on relationships and the transition into parenthood
- ✓ Advice on child development, parenting skills and information on child care services

Pre-conceptual advice on drug use can include:

- ✓ The risks associated with smoking in pregnancy and information on smoking cessation
- ✓ The risks of moderate to excessive alcohol use in pregnancy and advice on how to cut down consumption
- ✓ Information on alcohol services in Lothian and how to access them
- ✓ The risks associated with illicit drug use, in particular injecting drug use
- ✓ The risk of Neonatal Abstinence Syndrome (NAS) in babies born to dependent mothers
- ✓ Options for drug management in pregnancy and the importance of substitute prescribing and stability for opiate dependent women
- ✓ Information on drug services in Lothian and how to access them
- ✓ Testing for blood borne viruses (HIV, hepatitis C & hepatitis B)
- ✓ Information on mother-to-baby transmission of blood borne viruses and how this can be reduced

All women with a poor obstetric or medical history, or a previous poor fetal or obstetric outcome, or a family history of significant illness should be offered specific pre-conception services (Scottish Executive 2001). The woman should be encouraged to discuss this with her General Practitioner in the first instance.

Antenatal care

Antenatal care

Receiving good quality antenatal care is known to improve pregnancy outcomes, irrespective of continued drug/alcohol use (Department of Health 1999). **All women with substance misuse problems should be told about the benefits of antenatal care and advised to attend early in pregnancy.**

Maternity care in Lothian is now essentially *community based* and *midwife* managed. Care is '*individualised*' and depends on the needs of the individual woman and her circumstances. Midwives follow an '***Care Pathway***' for antenatal and postnatal care, which includes routine antenatal appointments, screening tests and other procedures during pregnancy (depending on parity), parenthood education, preparation for childbirth and postnatal visits.

Community midwives and GPs now successfully manage the majority of pregnant women with substance misuse problems. All women identified as having a drug or alcohol related problem should have **two** named midwives involved in their care to ensure continuity of care. The Consultant Obstetrician is informed of the woman's drug and/or alcohol use and will jointly manage her care in the community. Most Consultant Obstetricians now run *outreach clinics* in community health centres throughout Lothian and can see the woman close to her place of residence. Only a small number of substance-misusing women need to be referred to the '*high risk' clinic* for management by the obstetrician, and this is normally for other pregnancy complications (e.g. HIV positive).

All pregnant women receive a copy of the '***Ready Steady Baby***' book (produced by NHS Health Scotland), which contains comprehensive information on all aspects of pregnancy, childbirth and postnatal care and will help the woman in her decision-making. The GP will normally give a copy of the book to the woman at confirmation of pregnancy or the midwife will give it to her at booking.

Hand held maternity records

All pregnant women now receive a unified multi-professional *woman-held* maternity record. This is normally given to the woman at around 16 weeks

gestation and she keeps it until she is admitted into hospital for delivery. The woman is encouraged to contribute to her notes if she wishes. **Record keeping is an integral part of care.** All professionals involved in a woman's care should ensure that important information is *put in writing* and included in the woman's maternity record. Guidance on the terms of the Data Protection Act 1998 (see leaflet '*Protecting personal health information*') and confidentiality, need to be explained to the woman. The **consent form** for sharing information between professionals involved in the woman's care should also be included in the woman's notes (see *appendix 5*).

The 'booking appointment'

As early as 6 weeks of pregnancy the woman can attend for a 'pre booking' appointment with the community midwife to start her antenatal care, although this is not routinely offered. Pregnant women can either self refer to the midwifery team, or be referred by their GP or other agency.

The *booking appointment* is normally arranged for 12 weeks gestation and is a very important appointment for the woman to attend. At the booking appointment the midwife completes a *comprehensive assessment* of the woman's needs and will plan pregnancy care with the woman. The midwife also undertakes a *risk assessment* to take into account any factors that might affect pregnancy outcome and the woman's ability to care for her baby. All women receive their care in the community unless they have been identified as '*high risk*', in which case they will have their care managed by a Consultant Obstetrician who may arrange for their care to be delivered in the hospital.

At the booking appointment the midwife *routinely* asks about all drug use, including smoking, alcohol use, illicit drug use and prescribed drug use. Drug taking details are recorded in the woman's *hand held maternity record*, unless she requests otherwise.

Women who have a drug or alcohol related problem are asked to provide information for the ***'Antenatal liaison form (Substance Misuse)*** (see *appendix 9*) which provides maternity staff with more detailed information on the woman's drug/alcohol use and social circumstances. This form is included in the woman's records and will follow her through

the antenatal ward, labour ward, and postnatal ward. This enables intrapartum and postpartum care to be co-ordinated and tailored to the special needs of the woman and baby whilst in hospital. If the woman does not want the form to be included in her hand held records (for instance because of concerns about confidentiality) then it should be filed in the *supplementary notes file* which is held in hospital admissions (RIE).

At booking, the community midwife should give all pregnant women with drug and alcohol related problems a copy of the **information booklet** called '***Pregnant… and using alcohol or drugs?***' (see *appendix 11*). The woman and her partner should be advised to read the information booklet then discuss any questions or anxieties that they may have at their next antenatal appointment.

It is important to remember that for some women their drug and alcohol use may come to light for the first time because of their pregnancy care. If this happens there is an excellent opportunity for **harm reduction advice** and education to be offered and may lead to a change in the woman's drug use. Other women may know they have a drug or alcohol related problem but choose *not to disclose* this information to health and social care professionals. Some women may acknowledge that they use alcohol or drugs but grossly under-report their use. These women are sometimes identified when problems manifest in the neonate, at which point help can be offered.

Many women with drug related problems in Lothian are already known to drug services and will be on prescribed methadone or dihydrocodeine (DF118) and perhaps diazepam as well. Some will be receiving their prescription from the *Community Drug problem Service* (CDPS), or *Harm Reduction Team* (Low Threshold Methadone clinic) but most will be attending their *General Practitioner* for their prescribed drugs. A small number of HIV positive women drug users receive prescribed opiates from the *Regional Infectious Diseases Unit* (RIDU) at the Western General Hospital.

Routine antenatal screening at booking

At the booking appointment, the community midwife will also offer '*routine antenatal screening*'. Blood samples are taken for: HIV, hepatitis B, rubella, syphilis, blood group and a full blood count.

Please note the following regarding **blood borne viruses**:

- Women who are currently injecting drugs or who have a history of *injecting drug use* may be at risk of HIV, hepatitis B and hepatitis C.
- The hepatitis B *vaccine* can be given safely in pregnancy and should be offered to all women who are likely to inject drugs in pregnancy or whose partner is an injecting drug user.
- The Hepatitis C antibody test is *not* offered routinely as part of antenatal care in Lothian, however it *should* be offered to all pregnant women at risk.
- Many women who use drugs may *not* have a history of injecting themselves, but may have a *partner who does*.
- Non-drug using women may be at risk of blood borne virus infection if they have *unprotected sex* with an infected man.

For more detailed information on **antenatal testing for HIV, hepatitis B and C** and the **management of positive women and their babies** see *appendix 1*.

Other screening and diagnostic tests

Numerous screening and diagnostic procedures are offered during pregnancy. These are especially important for drug and alcohol using women who may be at increased risk of pregnancy complications. Drug use is associated with an increased risk of **intrauterine growth restriction (IUGR)** so care should be taken to assess fetal growth by clinical examination, ultrasound and antenatal fetal monitoring. Staff should be careful to explain the reasons for any additional tests sensitively to the woman.

Ultrasound scan is normally arranged for 10 – 14 weeks. It is important partly to confirm gestational age, but also to provide the mother with a positive experience of the hospital. Substance-misusing women often worry about fetal abnormality more than any other problem and feel guilty about the damage they may have caused their baby. In general, it is

usually possible to be quite reassuring (Johnstone 1998). Detailed **fetal anomaly scanning** is not normally required as substance misuse is not associated with an increased risk of structural fetal abnormality. The only exceptions would be with heavy alcohol consumption (>8 units/day), cocaine or amphetamine use.

Attendance for **fetal monitoring** (cardiotocography or CTG) may sometimes be necessary for substance-misusing women, particularly if growth restriction (IUGR) is established. Please note however that there may be reduced activity (loss of variability and accelerations) following ingestion of opiates, benzodiazepines and alcohol. Repeat or extended monitoring is sometimes required. The **biophysical profile** is less affected and will usually be normal even after ingestion of drugs. Another fetal monitoring test, the **umbilical artery doppler** assessment, can identify vascular problems in the placenta, which can lead to distress or death. This test might be necessary for women who are heavy users of stimulant drugs (such as cocaine or amphetamines) or women in whom IUGR is demonstrated by ultrasound.

Some women drug users (for instance those working in the sex industry) are at higher risk of **sexually transmitted and other vaginal infections**. Because infections are a risk factor in pre-term labour and delivery it is important to detect and treat all infections in pregnancy. Screening for chlamydia, gonorrhoea, bacterial vaginosis and Group B streptococcus should be considered.

Some women (in particular HIV positive and immuno-compromised women) may also be at greater risk of **cervical intraepithelial neoplasia (CIN)** and may not have attended for routine cytological screening (cervical smears). Pregnancy can be a good opportunity to attract women into cytological surveillance, certainly in the 1st and early 2nd trimester.

Pregnancy complications

Other complications can occur in substance-using women but not much more frequently than other women, with the exception of women using large amounts of stimulants, such as cocaine (Johnstone 1998).

Pre-term labour is a particular problem that poses a difficult start to mothering and is a significant risk to the baby. It is more common in drug dependent women, particularly those using drugs intravenously or taking short-acting opiates (i.e. heroin). Very pre-term delivery is associated with increased mortality. **Infections** also account for some pre-term labour episodes so screening is advisable. Pregnant women should be advised to present themselves *early* if they think they are in pre-term labour so that an injection of steroids can be given to help mature the fetal lungs.

Maternal health problems

Good nutrition in pregnancy is important for the development of the baby. All pregnant women should be given advice about eating a **healthy balanced diet**. Pregnant women are routinely tested for **anaemia** at their antenatal appointments and will be prescribed iron if necessary. They are advised to take **folic acid** for the first 12 weeks of pregnancy to prevent neural tube defects. **Constipation** is very common in pregnancy and can be exacerbated by opiate use, so women should be advised to increase their fibre intake and drink more water.

Poor general health and drug use can lead to **respiratory problems**, including chest infections and asthma. Repeated injections over years destroys peripheral veins, often leaving 'track marks' so **venous access** may be limited even in women who stopped injecting drugs years before.

Good **dental care** in pregnancy is especially important. All pregnant women with substance misuse problems should be encouraged to attend their dentist for a check up so that they can get any necessary dental treatment and avoid dental decay and infections in pregnancy. Severe dental problems are commonly associated with opiate use. This is made worse by the high sugar content and acidity of **methadone**. *Sugar free* methadone is available on prescription, but the acid content is similar to the normal preparation. Advise all women to brush their teeth with fluoride toothpaste *before* they take their methadone and rinse their mouth afterwards with water. Sugar free chewing gum will also help clear the methadone from their mouths. Women tend to suffer increased gum problems during pregnancy, which can show itself as bleeding gums. This

can be more serious in women with substance misuse problems and progress to acute and very painful infections.

There is a *dental drop-in clinic* at the Harm Reduction Team (HRT) in Spittal Street Centre on Mondays and Wednesdays (11am-1.30pm). This free dental service is available to all drug users who are attending the CDPS, HRT and Locality Clinics. Tele. 0131 537 8323 to make an appointment or advise the women to attend the drop-in clinic.

Benefits and allowances

All pregnant women should be given information on *benefits and allowances* that are available during and after pregnancy. These include:

- ✓ Entitlement to ***free NHS prescriptions*** throughout pregnancy and for one year after the birth of their baby
- ✓ Entitlement to ***free NHS dental treatment*** throughout pregnancy and for one year after the birth of their baby
- ✓ The ***'Sure Start' Maternity Grant*** (which is currently worth £500 and can be claimed from 29th week of pregnancy). A midwife, health visitor or doctor can sign this form (which confirms that the woman has received health education and antenatal care).
- ✓ Entitlement to ***free milk*** tokens after the birth of their baby

Further information on benefits is available from the ***Welfare Rights Advice Shop*** (see *services* list) and the **Social Security booklet** '*Babies and Children: A basic guide to benefits and tax credits for anyone expecting a baby or caring for children'* (BC1 2003). Tele. 0800 882200 for a copy.

Preparation for parenthood

All pregnant women and their partners are offered 'parent education' and this normally starts at around 32 weeks gestation. Group and individual sessions are organised and run jointly by Midwives and Health Visitors. Parent education is especially important for women with substance misuse problems and for first time mothers and fathers. All parent education sessions are community-based. For further information contact the local Community Midwifery Team. Professionals should encourage parents to attend these sessions as many people with substance misuse problems have not had positive parenting role models and attendance is often poor.

Risk assessment

Risk assessment during pregnancy

All professionals working with pregnant women with substance misuse problems should have a clear understanding of the concept of *risk assessment* to ensure **safety for mother and baby**. Risk should be **continuously** assessed throughout the pregnancy, taking into account that risk status is dynamic and may change over time (Scottish Executive 2001). See section on *assessment*, page 25.

Significant **risk factors** that would warrant further assessment and intervention would include:

- ✓ Poor obstetric and pregnancy outcome history
- ✓ Poor maternal health / significant illness / HIV, Hepatitis C or B
- ✓ High alcohol consumption or alcohol dependence
- ✓ Injecting drug use or chaotic illicit (non-prescribed) drug use
- ✓ Neonate at risk of developing Neonatal Abstinence Syndrome (NAS), or previous baby with NAS
- ✓ History of severe mental health problem (e.g. schizophrenia, bipolar disorder, postnatal depression / puerperal psychosis, eating disorder)
- ✓ Domestic abuse
- ✓ Homelessness and insecure/ unsuitable/ unsafe accommodation
- ✓ Other significant social problems (e.g. legal, financial, unsupported pregnancy, chaotic lifestyle)
- ✓ Existing children on 'at risk' register / accommodated by local authority
- ✓ Recorded history of previous parenting or child care concerns

Homelessness

Pregnant women who are homeless or in temporary accommodation can register with a GP at the Edinburgh Homeless Practice, either at the Access Point on Leith Street or at the Cowgate Clinic in the Grassmarket. The Access Point has social work and housing department staff who work in a multi-disciplinary team alongside health care staff. All pregnant homeless women are referred to the South East Edinburgh community midwifery team at *Craigmillar Health Centre*. The midwife will arrange to visit the woman at the clinic or in temporary accommodation. It is important that the woman finds suitable accommodation in time for her to prepare for the birth of her baby. Homelessness creates additional stress

for the women and can make attendance for antenatal care difficult. Good liaison and care planning are required to ensure agencies are working together. Pregnant women also need to engage early with the Health Visiting service who will encourage the family to move towards accessing mainstream services once they are in stable accommodation. For other services for homeless people see '*services list*'.

Not registered with a GP

Pregnant women who are not registered with a General Practitioner should be encouraged to do so as soon as possible. If the woman experiences any difficulty registering with a GP then she should be advised to contact Primary Care Services to request a GP be 'allocated' to her. Requests must be made in writing. Advise the woman to complete the *proforma* letter (see *appendix 6*) and send to Lothian Health Primary Care Services. Tele. 0131 537 8473 for enquiries. The process of being allocated a GP normally takes about one week.

Domestic abuse

Domestic abuse can have a harmful, sometimes even life-threatening, impact on the physical and mental wellbeing of both mother and baby and is a serious criminal, social and medical problem. Domestic abuse can include a wide range of *physical* (e.g. hitting, kicking, restraining), *sexual* (including rape and coercion), *psychological* (verbal bullying, undermining, social isolation) and *financial* (e.g. withholding money) abuses. Domestic abuse is widespread and under reported and the level of repeat incidence is high. *Conclusive evidence has demonstrated that pregnancy, far from being a time of peace and safety, may trigger or exacerbate male violence in the home* (Royal College of Midwives 1997). Violence may also increase following the birth of a child or when a woman tries to end a relationship (Scottish Executive, March 2003). All midwives should sensitively enquire about domestic abuse as part of their antenatal risk assessment. Relevant addresses and telephone numbers should be made easily accessible to enable women to get help with or without the support and knowledge of health and social care staff. Women who disclose domestic abuse should be given advice and support on how and where to get help. Details of services that offer psychological support as well as refuge are included in the *services* list.

Health care staff can refer to the Scottish Executive document '*Responding to Domestic Abuse: Guidelines for Health Care Workers in NHS Scotland*' (March 2003) for further guidance. All professionals can obtain free copies of the Scottish Executive booklet '*Domestic Abuse: There is no excuse*' (Tele. 0131 244 3995).

Neonate at risk of Neonatal Abstinence Syndrome (NAS)

It is important to discuss at an early stage with all drug dependent women the possibility of *Neonatal Abstinence Syndrome (NAS)*. She needs to know that NAS is usually easily managed but the baby will need her support, understanding and patience. Having a baby who develops severe withdrawal symptoms can be very distressing for parents, but if properly looked after the baby will make a full recovery and will come to no short-term developmental harm (Johnstone 1998). In Lothian, a **parent information leaflet** called '***Caring for a baby with drug withdrawal symptoms***' is available (see *appendix 12*). This leaflet should be given to all drug dependent women and their partners at around 32 weeks gestation. They should be advised to read the leaflet and discuss their birth plan and care of their baby with the midwife. For more detailed information see section on NAS, page 43.

Child care risk

Occasionally, a risk assessment will identify concerns about the ability of the woman (or her partner) to look after their (currently unborn) child. If this is the case, then it is important to address these concerns with the woman at an early stage. All professionals in contact with pregnant women have a responsibility to act if they believe that the baby's safety or welfare will be at significant risk of harm. A pro-active and **early intervention** approach is more likely to result in a positive outcome for both mother and baby.

Professionals should make themselves familiar with:

- Edinburgh and the Lothian's '**Child Protection Guidelines**' (Nov 2002),
- '**Getting Our Priorities Right: Good Practice Guidance for Working with Children and Families affected by Substance Misuse**' (Scottish Executive 2003), and
- **'Hidden Harm: Responding to the needs of children of problem drug users'** (ACMD report 2003).

These documents contain important information for professionals, including:

- ✓ The guiding principles of child protection
- ✓ The legal framework on child protection
- ✓ Professional roles and responsibilities in relation to protecting the welfare of children
- ✓ Guidance on information sharing and confidentiality
- ✓ The signs and symptoms of physical abuse, neglect, non organic failure to thrive, emotional abuse and sexual abuse
- ✓ The impact of parental problem drug use on infants and children
- ✓ The referral process for dealing with child care concerns and child protection issues
- ✓ A checklist of information to be collated concerning substance misuse and its impact on parenting
- ✓ The practicalities of protecting and supporting the children of problem drug users
- ✓ A helpful contact list of professionals who have expertise in child protection within Lothian

For more detailed guidance on dealing with child care concerns see section '*Assessing and Managing Child Care Risk during Pregnancy*', page 95.

Intrapartum care

Intrapartum care (labour and childbirth)

The vast majority of labours and deliveries will be straightforward in drug and alcohol using women and thus their care will be similar to any other woman (Johnstone 1998). There are however, a few important factors to consider.

Currently, intrapartum care in Lothian is provided by labour suite midwives and community midwives who staff the labour suite on rotation. The pregnant woman may see a number of different midwives if she has several antenatal episodes in the labour suite (for instance for pre-term labour) and her key midwife in the community may not be the one who delivers her baby.

The *Obstetrician* and *Paediatrician* are kept informed during labour, but they are not the key professionals unless there are complications (for instance, pre-term delivery).

Midwives delivering intrapartum care should make sure they read the woman's *hand held records* and any other confidential or '*sensitive*' information kept in the *supplementary notes file* held in admissions (R.I.E.). The ***antenatal liaison form (substance misuse)*** provides detailed information on the woman's drug / alcohol use, medication, pharmacist and key professionals and services involved in her care (see *appendix 9*).

Maternity hospital policy

The woman, her partner and family all need to understand the hospital priority for a safe pregnancy and childbirth experience. This means zero tolerance of illicit drug use on hospital premises, clear limits on the number and conduct of herself and any visitors, and zero tolerance for abusive, threatening or aggressive behaviour. If necessary, visitors will be removed from the building and barred from returning.

Substitute prescribed drugs are dispensed by the hospital pharmacy but only after the dose of medication has been checked with the prescribing doctor and any community prescriptions have been cancelled with the pharmacist. This means that hospital staff will need to know the name and telephone number of the *prescribing doctor* and

pharmacy. This information should be written clearly on the ***antenatal liaison form (substance misuse)***. The woman should remember to take any supply of medication into hospital with her, *as it will not be replaced* if it has already been dispensed in the community. On discharge, the hospital will notify the prescribing doctor when the next dose of medication is due to be dispensed from the community.

Pain relief during childbirth

Women who use drugs may be fearful of labour and childbirth and worry that they will not get adequate pain relief. *It is very important that adequate pain relief is given* and the midwife establishes a good rapport with the woman, offering reassurance and support when required. It is a good idea to discuss pain relief options in the *antenatal* period so that the woman feels confident that she will be well cared for and treated like any other woman in labour.

Prescribed medication should be dispensed *as normal* during labour. **Substitution treatment with methadone or dihydrocodeine does not provide pain relief.** Opioid receptors may be saturated so higher doses or more frequent injections of diamorphine are likely to be needed (Sparey & Wilkinshaw 1999). There is usually a low threshold for an *epidural* anaesthesia and many drug dependent women opt for this pain management approach.

Caesarean section is no more likely than in the normal population and having a history of drug misuse should not be considered a contraindication to having a PCA pump (patient controlled analgesia pump) following caesarean section (Siney 1999). Post delivery pain relief should be the same as for every other woman, although higher doses may be required.

Complications of childbirth

In women with a history of injecting drug use, **venous access** may be poor and antenatal referral to an anaesthetist may be required. Where labour is straightforward, no intravenous line is required. However, if it appears that there might be complications, it is sometimes better to establish an intravenous line *electively* shortly after admission, rather than be faced with the task in an emergency situation (Johnstone 1998).

There may be **placental insufficiency** in pregnancies of drug-using women, leading to an increased risk of intrapartum hypoxia, fetal distress and meconium staining (Department of Health 1999). **Meconium aspiration** is common and is associated with fetal distress secondary to periods of intra-uterine drug withdrawal. Some babies will be **growth restricted** so there should be careful surveillance during labour. Maternity staff should follow hospital guidelines for obstetric and neonate management for *meconium staining*.

High dose benzodiazepine use in the mother can result in the newborn showing *signs of intoxication* at birth that include: poor sucking, poor reflexes, hypotonia (low muscle tone), hypothermia (low body temperature), a feeble cry and low APGAR scores. Severely affected neonates may require vigorous resuscitation at birth because of respiratory depression. Women who are anxious about childbirth should be warned not to 'self medicate' with non-prescribed benzodiazepines (e.g. Valium®) before they admit themselves for delivery.

Please note: Labour ward staff **must not use *naloxone*** (an opiate antagonist) to reverse opioid induced respiratory depression in neonates as this will induce an abrupt opiate withdrawal crisis. Use supportive measures or ventilation if necessary.

Postpartum care in hospital

After delivery, the labour ward midwife should liaise with staff in the postnatal ward to ensure continuity of care. The *key midwife* in the community should also be informed of the delivery. This is particularly important if the woman has delivered pre-term. Maternity staff providing intrapartum care should complete the ***pregnancy outcome form (substance misuse)*** (see *appendix 9*).

All known drug dependent women are asked to stay in hospital for three days **(72 hours)** following the birth of their baby. This is because the baby needs to be observed for signs and symptoms of **Neonatal Abstinence Syndrome (NAS)**, which normally develop within this time period (see section on NAS for further information, page 43).

Confinement in hospital can be a threatening experience for some drug-using women (Mounteney 1999). Staff should take care to *ensure privacy* by being discreet about the administration of any medications (e.g. methadone) so that the woman's drug use is not exposed to other patients or visiting relatives who might not know about her drug use.

Soon after delivery, mother and baby should be transferred to the **postnatal ward** where they can '***room in***' together and have '***skin-to-skin***' contact. Separating mother and baby should be avoided if at all possible. '*Skin-to-skin*' contact will help the baby relax and sleep, regulate their body temperature, steady their breathing, help with mother-infant bonding and will help get breastfeeding off to a good start.

Women who have a history of alcohol related problems (who remain in the postnatal ward) can be observed for maternal symptoms of **alcohol withdrawal** (which typically occur around 48 hours post delivery), in which case appropriate medication may be required (Wright & Walker 2001).

Ideally, discussion about the need for **postnatal contraception** should have been instigated in the antenatal period rather than at the post-delivery meeting before discharge from hospital. Many women with substance misuse problems are not able to address their reproductive and sexual health care needs adequately. Planning contraception for the postnatal period involves considering 'what, how and when?' to start using hormonal treatments (e.g. combined oral contraceptive pill, progestogen-only pill, 'Depo-Provera®', 'Implanon®' etc) or the coil. Advice on choices also varies depending on whether the woman is breastfeeding or not. Condoms are normally recommended for the first 48 hours post-delivery or for the first few weeks following delivery until hormonal contraception has been started.

After 72 hours on the postnatal ward, mother and baby can be safely **discharged** home, provided the baby is well enough. On discharge, all women are given a '*discharge pack*' which contains helpful information leaflets on caring for their baby.

In circumstances where the mother insists on taking an early discharge, she should be seen by the paediatrician and asked to sign a form that

states she is taking the baby home *against medical advice*. In rare cases, the mother may take her own discharge and leave the baby in hospital. If this happens, the baby will be transferred to the Neonatal Unit / Special Care Baby Unit (SCBU) for continued monitoring.

Infant feeding

Infant feeding

Much confusion surrounds the issue of whether a woman should breast feed her baby when continuing to take drugs. Many women and their partners are concerned about breastfeeding whilst taking drugs or drinking alcohol and will ask for advice. Parents should be informed that the benefits of breastfeeding *far outweigh* the disadvantages, even with continued drug use. It is important to reassure the mother that the actual amount of most drugs passed to the baby through breast milk is minimal and will have little effect on the newborn baby (Johnstone 1998). The sometimes small effect on the baby may even help withdrawal symptoms, if they are present.

It is important that the woman is not given contradictory advice from different professionals, as nothing is more certain to reduce her confidence and to confuse her decision-making.

Breastfeeding

Department of Health (1999) guidance recommends that *breastfeeding should be* ***encouraged*** in drug-using women. Mothers who are on prescribed drugs should therefore be encouraged to breast feed in the same way as other mothers. The exceptions to this would be if she were:

- HIV positive (because of risk of transmission)
- using large quantities of stimulant drugs, such as cocaine, 'crack' or amphetamines (because of vasoconstriction effects)
- drinking heavily (>8 units/day) or taking large amounts of non-prescribed benzodiazepines (because of sedation effects).

Breastfeeding is best done immediately *before* taking medication and should be avoided for one to two hours after any dose of medication (i.e. the time of highest plasma concentrations). Medications are best taken as a single dose where possible and should be administered before the baby's longest sleep period (SIGN '*Postnatal Depression'* guideline 2003).

There is no evidence that Hepatitis C transmission occurs through breastfeeding so mothers who are **Hepatitis C positive** should be encouraged to breastfeed (Scottish Executive 2003).

Women who are **Hepatitis B positive** can also safely breastfeed as soon as their newborn baby has had their first dose of immunoglobulin and Hep B vaccine (administered soon after birth).

Injecting drug use whilst breastfeeding should be discouraged because of the risk of mother-to-baby HIV transmission (see *appendix 1* for further information on *Blood Borne Viruses*).

Ideally the woman should keep her drug use as **stable** as possible whilst breastfeeding. Ability to successfully breastfeed is in itself an indication of stability (Hepburn 1996). Breastfeeding can support the mother in feeling that she is positively comforting and caring for her baby and it can aid in the bonding process. Breastfeeding will also benefit the long-term health of both mother and baby.

The benefits of breastfeeding are outlined in the UNICEF leaflet '*Feeding Your New Baby*', which mothers-to-be should be given in the antenatal period. For more detailed information about breastfeeding see '*Breastfeeding: Off to a good start*', available from NHS Health Scotland (previously HEBS).

Midwives can also offer a great deal of support and advice to mothers who wish to breastfeed their baby. For instance, they show the mother how to position their baby for feeding and how to make sure the baby attaches properly to the breast. They also teach mothers how to recognise when their baby is feeding properly and when not. Most areas throughout Lothian also have '*breastfeeding support groups*' and antenatal breastfeeding workshops. Contact the local Community Midwifery Team or Health Visiting office for further information on these.

Weaning

The World Health Organisation (WHO 2001) recommends that babies should be exclusively breast fed until about 6 months of age in order to achieve optimal growth, development and health. After 6 months of age, the mother can introduce appropriate solid foods whilst continuing to breastfeed for up to 2 years or beyond.

Formula (bottle) feeds are not a necessary part of a weaning diet. However, if a breastfeeding mother wishes to combine formula feeding with breastfeeding or to switch to formula feeding *she should do this gradually*, substituting one formula feed for one breast feed per day for several days, allowing her baby and her body to become accustomed to this. A second formula feed can then be introduced for another few days, then a third, fourth etc. Ideally, the weaning process should take several weeks, allowing a slow withdrawal for the baby.

Abrupt cessation of breastfeeding may result in the baby showing some signs and symptoms of drug withdrawal. Advise breastfeeding mothers who continue to take drugs to gradually introduce solids slowly into the breastfeeding schedule, reducing the frequency of breast feeds over a number of weeks.

Women with substance misuse problems should seek advice about weaning from their Health Visitor. Health care staff can seek advice from the *Infant Feeding Advisors* at the R.I.E. (Tele. 0131 242 2502) and Primary Care Trust (Tele. 0131 537 4262).

Bottle feeding

Many women drug users choose to bottle feed rather than breast feed. Social and cultural beliefs and norms are powerful influences on decision making about early infant feeding. Parents should be supported to make an informed choice about how to feed their newborn baby. Having made their decision, they should be supported by all professionals involved.

Postnatal care

Postnatal care

The care of a pregnant woman who uses drugs or alcohol and the safe delivery of her baby is just the start of care. **Continuing support in the postnatal period and for parenthood is essential if the ideal outcome of maintaining a healthy mother and child together is to be achieved.**

After discharge from hospital, the baby is cared for at home by the mother and family, with advice and support from the **Community Midwife** as well as other professionals and agencies involved with the family. The midwife will visit the family at home each day until the baby is 10 days old. Occasionally the midwife may need to continue visiting up until the baby is 28 days old, depending on how well the baby is and how well the mother is coping. The **Health Visitor** normally visits after day 10 and should liaise with the midwife and GP before visiting the family. The Health Visitor will be a good source of information and support on motherhood and all aspects of health for the woman and her baby. When the baby is 6-8 weeks old, the GP and Health Visitor will arrange a comprehensive postnatal examination of mother and baby.

Postnatal care should facilitate women and their partners to make an effective **transition into parenthood**. Professionals should give women and their partners an opportunity to reflect on their experiences of pregnancy and childbirth in the postnatal period as well as an opportunity to discuss the effects of parenthood on their relationships (Scottish Executive 2001).

Soon after mother and baby are home, a **case discussion meeting** should be organised by the 'lead professional' to review the care plan and to decide whether an appropriate level of support is in place for the family (Department of Health 1999).

Postnatal depression

Women drug users may be more at risk of *postnatal depression* and other mental health problems. Anxiety, depression and a history of sexual and/or physical abuse are commonly associated with drug and alcohol dependency. Identifying, screening and supporting women at risk of postnatal depression is very important. Untreated postnatal depression is

associated with detrimental effects on infant development. Postnatal depression is assessed using the *Edinburgh Postnatal Depression Score* (EPDS) screening tool and augmented by a multi-disciplinary *Integrated Care Pathway* (ICP). Health Visitors and GP's are trained to use these tools to improve the care of women at risk. Staff should make themselves familiar with the new SIGN guideline (2003) '*Postnatal Depression and Puerperal Psychosis*' (www.sign.ac.uk).

Sudden Infant Death Syndrome (SIDS)

Maternal tobacco use, as well as drug and alcohol misuse are associated with an increased risk of *Sudden Infant Death Syndrome* ('SIDS' or 'cot death'). All parents who use these drugs should be given advice about how to *reduce the risk* of cot death. The leaflet '*Reducing the risk of cot death*' (produced by the Scottish Executive 2000) is included in the hospital 'discharge pack'.

Risk of relapse

In the postnatal period, increased drug and alcohol use is common. For women who have managed to reduce their intake during pregnancy or even come off drugs or alcohol, the risk of relapse to former levels of drug taking is high. There are a number of reasons for this, including:

- feeling that it's now OK to use again
- relief at having a 'normal' baby
- wanting to celebrate!
- the stress of caring for a new born baby (perhaps with NAS)
- 'baby blues' or postnatal depression
- poor support from partner or family
- anxieties about motherhood

It is important for professionals to acknowledge that relapse is common. Re-assessment of substance use and *careful drug management* is essential at this time, along with support to remain stable and to prevent relapse.

Ensuring the woman is engaged with a specialist drug and alcohol agency that can provide a relapse prevention service may be an *important part* of the postnatal care plan.

Relapse prevention support work can include:

- ✓ helping parents understand relapse as a process and as an event
- ✓ raising awareness of 'high-risk' situations and factors that might lead to relapse
- ✓ exploration of how to anticipate, avoid or cope with these high-risk situations
- ✓ acquisition of skills (cognitive and behavioural) to implement relapse prevention strategies
- ✓ anxiety and stress management education
- ✓ confidence building and improving self–efficacy
- ✓ strengthening existing positive coping strategies and other personal attributes
- ✓ life / social skills education (e.g. assertiveness, resistance and dissuasion skills, alternative activities to drug/alcohol use)

Assessing and managing child care risk

Assessing and managing child care risk during pregnancy

Many pregnant women who have substance misuse problems worry that they will be referred to social services or their baby will be taken into care purely because they use drugs. Raising this subject early and discussing their concerns openly will foster a more trusting relationship. **It is important to reassure women that substance misuse, in itself, is not sufficient reason to assume inadequate parenting or child care.** They need to know, however, that if there are specific concerns about the safety or welfare of the child then social work will need to do an assessment and get involved, but that this policy is the same for everyone, whether or not they use drugs. This advice is mentioned in the information leaflet '*Pregnant… and using drugs or alcohol?* (see *appendix 11*).

Many different factors affect the health and development of children. Parental drug and alcohol use is just one factor. Research evidence *does not* support the assumption that parental substance misuse will automatically lead to child neglect or abuse (Scottish Executive 2003). Indeed, a number of *case controlled studies* in Britain have found no significant differences in the health and development of children in drug-using households compared to non-drug using households (Ross et al 1995, Burns et al 1996). Becoming 'drug free' should not be a requirement for parents to keep their children living with them. Parents who stop using drugs or control their drug intake are not necessarily better or safer parents. Some parents will have poor parenting skills for reasons other than their substance misuse as many risk factors also occur in non-drug using families (Scottish Executive 2003).

However, a chaotic drug or alcohol using lifestyle *may* affect child safety and the child's health and development in a number of ways and is always a factor to be considered. Infants, in particular, are vulnerable to the effects of physical and emotional neglect or injury which can have damaging effects on their long-term development.

A number of **childcare problems** have been associated with parental substance misuse (Scottish Executive 2003, ACMD 2003). Some of these include:

- Inconsistent caring
- Inadequate supervision
- Lack of stimulation
- Inadequate and unsafe accommodation
- Social isolation and stigma
- Exposure to violence and criminal behaviour
- Emotional or physical neglect or abuse

Resulting in…

- Failure to thrive
- Accidental injury
- Emotional difficulties
- Behavioural difficulties
- Poor social development
- Poor cognitive and educational attainment

Professionals who are involved with children and families need to remember that good **inter-agency communication** and **collaboration** in the care process is essential. It is important to **obtain consent** from the woman early to share information with other professionals and agencies (see consent form in *appendix 5*). No professional, however, can guarantee absolute confidentiality as both statute and common law accepts that information may be shared in certain circumstances.

Child care risk assessment should cover issues such as existing parenting skills, child safety, as well as the physical, cognitive, emotional and social development of children. Drug and alcohol specialist workers that lack child care and parenting expertise should consult with and involve other professionals and agencies who do have this expertise.

The Scottish Executive (2003) document '*Getting Our Priorities Right: Good practice Guidance for working with Children and Families affected by Substance Misuse',* appendix II, includes a helpful ***checklist*** for collating information on substance misuse and its impact on parenting (download from www.scotland.gov.uk).

The assessment process (see pages 25-27 & 77-80) may highlight **concerns** because the woman or her partner:

- ✓ has a very chaotic lifestyle with multiple social problems and repeatedly fails to attend antenatal appointments
- ✓ attends appointments but are repeatedly intoxicated or incapacitated from the effects of alcohol or drugs
- ✓ has an inappropriate home environment which could be unsafe for a baby
- ✓ lacks the necessary material possessions for caring for a baby
- ✓ has been previously referred to social work regarding their parenting ability
- ✓ has existing children on the child protection register
- ✓ has had previous children accommodated by the local authority
- ✓ has had previous children adopted
- ✓ discloses domestic abuse
- ✓ is socially isolated with no support network

Child protection

The welfare of the child is the paramount consideration. All professionals working with pregnant women and families affected by substance misuse should make themselves familiar with Edinburgh and the Lothian's (Nov 2002) '***Inter-agency Child Protection Guidelines***'.

In line with these guidelines professionals who have concerns should consider taking one or more of the following **actions**:

- ✓ Contact your local duty social work service (Children & Families Team) to discuss your concerns and to seek their advice
- ✓ Refer to a **non-statutory service** that works with children and families affected by substance misuse (such as the ***Harbour Project*** or ***Aberlour Outreach Project***). Substance-misusing parents see non-statutory services as more acceptable and less 'stigmatising' than social work. Professionals who work in these services can offer intensive parenting support.
- ✓ Discuss your concerns with the Midwife, Health Visitor or General Practitioner
- ✓ Contact your designated senior staff member with responsibility for child protection to discuss your concerns

- ✓ Report your concerns to the Children's Reporter. Individuals and agencies have the right to make a referral to the children's reporter irrespective of the views of the local authority.
- ✓ Encourage the woman to approach social services herself for help and advice

If there is a **significant risk of harm** to the baby's health and development then **professionals should take action** and refer to social services. Significant harm may result from maltreatment or the absence of adequate care. The protection of children is an interagency responsibility, but ***social work*** has a statutory responsibility to assess risk and ensure that child protection plans are in place if necessary. The social work assessment, while acknowledging the needs and the rights of the parents, will focus primarily on the *needs and welfare of the child*. In some situations there will be conflict between the needs and wishes of the parents and the welfare of the child.

Any referral or discussion with social services should be **handled sensitively**. It is important to stress to the woman that social work involvement is often positive and helpful. Whenever possible, social work has a duty to promote children's upbringing by their families. Compulsory removal of children from their families is rare, even when agencies are worried about a child's welfare (Scottish Executive 2003).

Occasionally, social services will be sufficiently concerned about the future risk to an unborn child to warrant the implementation of **child protection procedures** and the calling of a ***child protection case conference*** to consider the need for registration and a child protection plan. If a *child protection case conference* is called, ideally it should be held 6-8 weeks before the estimated delivery date so that services can be put in place in time for the birth of the baby.

Early intervention strategies

For families who are of '*concern*' but not formally '*at risk*', professionals should take the opportunity to engage with the parents and **intervene early**. A range of interventions can be helpful for pregnant women and vulnerable children and families. These include offering **parenting support** by:

- ✓ Offering emotional support and an opportunity to talk about any stresses or worries
- ✓ Discussing parenting roles and responsibilities
- ✓ Developing the parents existing skills, attributes and resources
- ✓ Promoting a safer and more stable lifestyle
- ✓ Teaching strategies to develop good parent/infant bonding
- ✓ Offering or arranging practical support to the family
- ✓ Teaching good play techniques and parent/child activities
- ✓ Discussing strategies for managing their children's behaviour
- ✓ Engaging them in activities where they can experience positive role modelling
- ✓ Helping parents develop routines, guidelines and boundaries with their children

Protective factors

Professionals who provide care to pregnant women and their partners can ensure that '***protective factors***' **in child welfare are promoted** by *routinely* discussing the following topics both *before* and *after* the baby is born:

- ✓ Drug safety issues in the home… safe storage of drugs, safe storage and disposal of injecting equipment, risks of ingestion of drugs and overdose, how to deal with medical emergencies etc
- ✓ The importance of providing for all the child's basic needs… food, clothes, warmth, personal hygiene, comfort, safety, stimulation, age-appropriate activities etc
- ✓ The importance of attending any child health appointments with the doctor and Health Visitor (Public Health Nurse)
- ✓ The importance of providing appropriate supervision for their children… periods of intoxication and withdrawal may be a time when adequate supervision cannot be provided and parents will need to ensure that another responsible adult is available in these situations
- ✓ Outlining potential problems… such as a chaotic substance-misusing lifestyle, other drug-using friends and households, procurement of drugs, violence, drug dealing, offending behaviour etc which may put the child at risk
- ✓ The importance of establishing daily routines and making the home safe and secure for the child

Finally, it is important to remember that the majority of pregnant women and parents with substance misuse problems will provide adequate care for their children and most children will remain living with their birth parents.

Pregnancy is a special event in the life of a woman with substance misuse problems and provides professionals with an opportunity to offer treatment and care that might not otherwise be accepted. The philosophy of approach and principles of management should be broadly the same as for any other pregnant woman with special circumstances and needs.

Services

Services List

Services providing maternity care in Lothian

Maternity services in Lothian are part of the acute sector. Approximately 6000 births per year are now delivered in Simpson's Centre for Reproductive Health at the Royal Infirmary of Edinburgh, Little France. In West Lothian 2000 births per year are delivered in the Maternity Unit at St John's Hospital, Livingston.

Maternity care is now essentially *community based* and *midwife* & *GP* managed. Most Consultant Obstetricians run *outreach clinics* in community health centres throughout Lothian. Both *Simpson's Centre for Reproductive Health* at the Royal Infirmary of Edinburgh and St John's Hospital *Maternity Unit* run 'high risk' pregnancy clinics.

Hospital maternity units in Lothian

- The Simpson Centre for Reproductive Health, Royal Infirmary of Edinburgh, 51 Little France Crescent, Edinburgh EH16 4SA.
  Tele. 0131 536 1000

- Maternity Unit, St John's Hospital, Howden Road West, Livingston, West Lothian EH54 6PP.
  Tele. 01506 419 666

Midwives are specially trained in pregnancy, childbirth and postnatal care. They are usually the lead professional for women with 'low risk' pregnancies. The midwife undertakes a *continuous risk assessment* throughout pregnancy and refers to other appropriate medical professionals if they detect deviations from the norm (Scottish Executive 2001). They also have a significant role in health education and in supporting parents in the transition to parenthood. All pregnant women in Lothian are allocated a named midwife at booking. This will normally be a midwife attached to their GP surgery.

Obstetricians/Gynaecologists are experts in all aspects of pregnancy and childbirth. Obstetricians have expertise in treating complications of pregnancy and childbirth and offering specialist advice, screening and treatment. Women with a *medium* to *high risk* pregnancy will have their

care managed by an Obstetrician, with midwifery and GP support. Throughout Lothian, obstetricians see most women at their outreach clinics in the local community.

Neonatologists and **Paediatricians** have the responsibility for looking after the medical needs of all babies, including pre-term infants, babies who are ill (for instance with Neonatal Abstinence Syndrome), and babies with congenital abnormalities. They work closely with obstetricians, midwives and neonatal nurses to plan and provide care for newborn babies in partnership with the parents. Neonates who are ill are normally cared for in the *Neonatal Unit* at Simpson's Centre for Reproductive Health at the Royal Infirmary or in the *Special Care Baby Unit (SCBU)* at the Maternity Unit at St John's Hospital, Livingston.

Health Visitors are nurses who specialise in family and public health and are part of the primary health care team. They work alongside midwives to provide parent education and support during and after pregnancy. At the point when the midwifery care ends (normally 10 days after birth) the Health Visitor takes responsibility for the mother, baby and family and will visit in the immediate postnatal period, then follow-up the child until the age of 5 years. Health Visitors play a key role in supporting families with breastfeeding, postnatal depression, diet, exercise, child health and development, disease prevention, parenting, behaviour management, social and emotional issues. Health Visitors visit pregnant women before they give birth and get involved in their care at an early stage. Health Visitors will soon be changing their title to '***Public Health Nurse***' in line with a move towards working with communities and groups to build their confidence in managing their own health.

General Practitioners have the responsibility for providing general medical care to the whole family and in most circumstances will confirm the pregnancy. GPs are experienced in caring for pregnant women and work closely with Community Midwives. Many jointly manage *antenatal care* in Primary Care Health Centres. They also work closely with obstetricians and midwives in providing care to women with 'high risk' pregnancies. GP's provide postnatal care to both mother and baby and work closely with Health Visitors. Many jointly manage '*baby clinics*' with Health Visitors to monitor the health and development of children. In Lothian, most people

with a *drug dependency* who are on substitute drugs are managed by their GP and attend primary care for their prescription. General Practitioner's will normally refer the pregnant woman to the community midwifery team and should provide details of any *substance misuse, prescribed drugs* or other *risk factors* on the referral letter or 'antenatal liaison card'.

Pharmacists work in partnership with patients, doctors and other health care professionals to ensure medicines are used safely and to best effect. Community pharmacists are easily accessible to pregnant women. Many are in frequent contact with pregnant women who are drug dependent (especially those on prescription medicines), so can provide support and health care advice. Pharmacists provide a wide range of services including: dispensing of 'substitute' prescriptions, supervised self-administration of methadone, needle exchange schemes and general health promotion advice. Pharmacists are also involved with smoking cessation programs such as *Want2Quit* which can help pregnant women and their partners stop smoking.

Link Midwives and Nurses (Substance Misuse)

In order to improve communication and care to pregnant women with drug and alcohol related problems in Lothian a *named midwife* in each community midwifery team in Edinburgh (and one each in East, Mid and West Lothian) as well as within the hospital midwifery department has been identified as a *Link Midwife for Substance Misuse*.

The **role and remit** of the Link Midwife (Substance Misuse) is:

- ✓ To support other midwives within their area to provide good quality care to women with significant problems related to alcohol and drugs
- ✓ To promote the implementation and use of the *Substance Misuse in Pregnancy* resource pack throughout Lothian
- ✓ To be a point of contact for other professionals involved in the care of substance-misusing women, offering information and advice where possible
- ✓ To liaise with *Link Health Visitors for Substance Misuse*, and other specialist drug and alcohol workers in their area
- ✓ To ensure all the midwives in their area use the substance misuse '*liaison forms*' and collate them for data collection purposes

- ✓ To attend regular meetings of the *Link Midwives* and keep up-to-date with trends, research findings, policy and good practice in relation to drug use (including alcohol and tobacco) in pregnancy.

To contact your local *Link Midwife for Substance Misuse* see list in *appendix 2*.

Link Health Visitors (Substance Misuse)

In order to improve the care of pregnant women, children and families affected by drug and alcohol related problems in Lothian a *named Health Visitor* in each LHCC (including East, Mid and West Lothian) has been identified as a *Link Health Visitor for Substance Misuse*.

The **role and remit** of the Link Health Visitor (Substance Misuse) is:

- ✓ To support other Health Visitors within their area to provide good quality care to children and families affected by substance misuse problems
- ✓ To promote the implementation and use of the *Substance Misuse in Pregnancy* resource pack throughout Lothian
- ✓ To be a point of contact for other professionals involved in the care of pregnant women, children and families affected by substance misuse
- ✓ To liaise with *Link Midwives* and specialist drug and alcohol service providers in their area to ensure channels of communication and referral are kept open
- ✓ To attend regular meetings of the *Link Health Visitors* and keep up-to-date with trends, research findings, policy and good practice in relation to substance misuse and child health.

To contact your local *Link Health Visitor for Substance Misuse* see list in *appendix 3*.

Drug services in Lothian

Most specialist drug services in Lothian **prioritise pregnant women and their partners** and will normally offer appointments within a few weeks from date of referral. Many also offer home visiting.

Lothian-wide drug services

- Community Drug Problem Service (CDPS), The Spittal Street Centre, 22-24 Spittal Street, Edinburgh EH3 9DU.
  Tele 0131 537 8343
  Health care service offering specialist assessment, substitute prescribing, drug stabilisation, supervision of methadone consumption, opiate detoxification, psychiatric assessment and drug management in pregnancy. *Written referral required*.
- Harm Reduction Team, The Exchange, Lady Lawson Street, Spittal Street Centre, Edinburgh EH3 9DU.
  Tele 0131 537 8300
  Offers needle exchange, advice about safer drug use, blood borne viruses and sexual health, and the low threshold methadone clinic for clients who continue to inject drugs. Offers choice of same sex worker. *Telephone or self referral*.
- Pharmacy Needle Exchanges
  There are approximately 20 pharmacies in Lothian currently participating in the needle exchange scheme. Contact Harm Reduction Team for an up-to-date list. Tele 0131 537 8300. *Please note that some local drug agencies also offer a needle exchange service – see list under 'local drug services'.
- Simpson House Drug Project, 52 Queen Street, Edinburgh EH2 3NS
  Tele 0131 225 6028
  City centre drug agency offering drug counselling (individual, couple and family), counselling for emotional problems relating to drug use, support to families of drug users and prison visiting. *Self referrals only*.
- Scot-Pep (Scottish Prostitutes Education Project), 70 Newhaven Road, Edinburgh EH6 5QG
  Tele 0131 622 7550
  Service for women working in the sex industry who have drug related problems. Offers needle exchange, information, advice and support.

- Crew2000, 32 Cockburn Street, Edinburgh EH1 1PB
  Tele 0131 220 3404
  Young People's (16-25 years) service offering information and one-to-one peer support for anyone using stimulant or hallucinogenic drugs (e.g. amphetamines, ecstasy, cocaine, crack, LSD).

Edinburgh-wide drug services

- Aberlour Outreach Project, 7 Hay Road, Edinburgh EH16 4QE
  Tele 0131 669 4317
  Offers support to families affected by drug and /or alcohol misuse who have children under 12 years. Support for pregnant women and help with positive parenting. Home visiting offered.
- Harbour Project, c/o Family Service Unit, 18 West Pilton Park, Pilton, Edinburgh EH4 4EJ
  Tele 0131 552 0305
  Offers support to families affected by substance misuse. Outreach service provided.
- Adult Resource Team Addictions (ARTA), Social Work Department, Building 4, 5-7 Regent Road, Edinburgh EH7 5BL
  Tele 0131 525 8040
  ARTA will assess, plan, co-ordinate and manage (for the first 16 weeks) an action plan of services to meet the needs of drug-using adults. *Written referral required*.
- Community Care Resource Team (HIV/Drugs), Social Work Department, Building 4, 5-7 Regent Road, Edinburgh EH7 5BL
  Tele 0131 525 8040
  Specialist community care service for people with drug-related problems and/or HIV infection who have complex care needs. Also provides community care assessments for residential drug rehabilitation placements.
- Hype, NCH Scotland, c/o Simpson House, 52 Queen Street, Edinburgh EH2 3NS
  Tele 0131 466 4600
  Service for young people (under 18 years) offering counselling, information, advice and support for those experiencing difficulties with drug, alcohol or volatile substance use.

Local drug services

- Locality Clinics (Drug Problems)
  Many areas of Lothian have *locality clinics*, most of which offer assessment of drug users, advice about and initiation of prescribing and review of drug users already on treatment whose management is causing concern. These clinics are usually run by a doctor with experience of caring for drug users, a nurse from the CDPS, and a worker from the local voluntary drug agency. *Written referral required*.

- Each geographical area throughout Lothian has its own **local drug service**. Most accept self referrals and offer information, advice, needle exchange, support, counselling and home visiting. Some provide specific services to women and families affected by drug use. Contact them for further information.

North West Edinburgh

- North Edinburgh Drug Advice Centre (NEDAC), 10 Pennywell Court, Edinburgh EH4 4TZ.
  Tele 0131 332 2314

North East Edinburgh

- Turning Point (Leith), 3 Smith's Place, Leith, Edinburgh EH6 8NT.
  Tel. 0131 554 7516

South West Edinburgh

- West Edinburgh Support Team (WEST), 12a Dumbryden Road, Edinburgh EH14 2AB.
  Tele 0131 442 2465

South East Edinburgh

- Castle Project, PO Box 922, Edinburgh EH16 4DU
  Tele. 0131 669 0068
- Greater Liberton Drug Project, Gilmerton Community Centre, 4 Drum Street, Edinburgh EH17 8QQ
  Tele 0131 664 2839

East and Mid Lothian

- Mid and East Lothian Drugs (MELD), 6a Newmills Road, Dalkeith, Mid Lothian EH22 1DU
  Tele 0131 660 3566
- AXIS, Tynepark, Poldrate, Haddington, East Lothian EH41 4DA
  Tele 01368 865351

West Lothian

- West Lothian Drug and Alcohol Service (WLDAS), 43 Adelaide Street, Craigshill, Livingston, West Lothian EH54 5HQ
  Tele 01506 430 225
- Drug Team (Social Work), Strathbrock Partnership Centre, 189a West Main Street, Broxburn, West Lothian EH52 5LH
  Tele 01506 775666

Residential drug services

- Links Project, Turning Point – Scotland, 5 Links Place, Leith, Edinburgh EH6 7EZ.
  Tele 0131 553 2222 (Referrals)
  Residential unit for men and women who wish to detox, stabilise or reduce their drug use. Stay of up to 6 weeks. *Self referrals only*. Clients from Mid, East and West Lothian require a community care assessment prior to admission.
- Brenda House, 7 Hay Drive, Edinburgh EH16 4QA.
  Tele 0131 669 6676
  Detoxification and rehabilitation unit for pregnant women and women with young children (under 12 years) who are drug or alcohol dependent. Community care funding required. *Self or written referrals accepted*.
- Midpoint Supported Accommodation (Turning Point), 9 Forrest Road, Edinburgh EH1 2QH.
  Tele 0131 226 5453
  Offers support for independent living, home visiting, practical and emotional support to women drug users who have their own tenancy.

Alcohol services in Lothian

Most specialist alcohol services in Lothian **prioritise pregnant women** and will normally offer appointments within a few weeks from date of referral. Most also prioritise work with any pregnant woman's **partner** who is affected by alcohol related problems too, so please make this clear when you refer.

Hospital

- Alcohol Problems Service (APS), 35 Morningside Park, Edinburgh EH10 5HD.
  Tele 0131 537 6557
  Offers specialist assessment, alcohol detoxification (in-patient and out-patient), psychiatric assessment and advice about management of alcohol use in pregnancy. *Written referral required*.
- Department of Psychological Medicine, Royal Infirmary of Edinburgh.
  Tele 0131 242 1396/1398
  Alcohol Liaison Nurses: Helene Leslie & Louise Learmonth
  Offers specialist assessment, advice and treatment regarding alcohol related problems to hospital in-patients.
- Liaison Psychiatry Service, St John's Hospital, Livingston, West Lothian.
  Tele 01506 419 666
  Liaison Psychiatry Nurse, Pauline McManus
  Offers specialist assessment, advice and treatment regarding alcohol related problems to hospital in-patients.

Community

- Alcohol Problems Service, Community Psychiatric Nursing Service, Royal Edinburgh Hospital.
  Specialist Community Psychiatric Nurses (CPN's) for people with alcohol related problems are located in each LHCC area. Contact APS or GP surgery for further information.
- Edinburgh and Lothian Council on Alcohol (ELCA), 2nd Floor, 40 Shandwick Place, Edinburgh EH2 4RT.
  Tele 0131 225 8888
  Lothian-wide service offering one-to-one alcohol counselling.

- Libra, 4 Norton Park, Edinburgh EH7 5RS
  Tele 0131 661 0111
  Lothian-wide service offering one-to-one counselling and support groups for women affected by alcohol problems.
- West Lothian Drug and Alcohol Service (WLDAS), 43 Adelaide Street, Craigshill, Livingston, West Lothian EH54 5HQ
  Tele 01506 430 225

Residential

- Brenda House, 7 Hay Drive, Edinburgh EH16 4QA.
  Tele 0131 669 6676
  Detoxification and rehabilitation unit for pregnant women and women with young children (under 12 years) who have alcohol related problems. Community care funding required. Self or written referrals accepted.

Smoking cessation services in Lothian

All areas throughout Lothian now have smoking cessation initiatives. For further information contact:

- Fiona Moore, Smoking Cessation Co-ordinator (Pregnancy)
  Tele. 0131 536 9414
- Jane Riddle, Smoking Cessation Co-ordinator (Primary Care)
  Tele. 0131 536 9415

West Lothian has a specialist midwife appointed to the '*Stop for Life*' programme at the Smoking Cessation Clinic at St Johns Hospital, Livingston, West Lothian.
Tele 01506 419 666 ext 3000

Other services in Lothian

A variety of other services may be of help to pregnant women depending on their needs. Please refer to services and resource list in '*Ready Steady Baby'* book as well as the following.

General

- The Housing Advice Centre, 23 Waterloo Place, Edinburgh EH1 3BH
  Tele 0131 529 7368
- Welfare Rights Team (Edinburgh Only), The Advice Shop, 85-87 South Bridge, Edinburgh EH1 1HN
  Tele 0131 225 1255

HIV

- Genito-Urinary Medicine Department (GUM), Lauriston Building (Level 4), Lauriston Place, Edinburgh EH3 9YW.
  Tele (Females) 0131 536 2104
  Offers HIV testing and care. HBV testing, STI testing and sexual health advice. Written or self referrals accepted.
- Regional Infectious Diseases Unit (RIDU), Ward 41, Western General Hospital, Edinburgh EH4 2XU.
  Tele 0131 537 2820/2823
  Testing and care for blood borne viruses. GP referral for people infected with HIV, HCV or HBV.
- Waverley Care, 58a Queen Street, Edinburgh EH2 3NS
  Tele 0131 226 2206 www.waverleycare.org
  Includes Milestone House residential service, 'Buddy' service and day care service.
- SOLAS, 2/4 Abbeymount, Edinburgh EH8 8EJ
  Tele 0131 661 0982
  Centre for support and information for people affected by HIV.

Hepatitis

- Centre for Liver and Digestive Disorders (CLDD), Royal Infirmary of Edinburgh, Little France.
  Tele 0131 242 3063

Specialist health service centre for liver disease. Offers assessment and treatment for people infected with hepatitis. Written referral only.

- Capital C, 13 East Norton Place, Edinburgh EH7 5DR
  Tele 0131 478 7929
  Lothian-wide service offering support to people infected or affected by hepatitis C. Offers information, advice and practical support in attending hospital appointments. Written or self referral.

Domestic abuse

- Scottish Women's Aid, Norton Park, 57 Albion Road, Edinburgh EH7 5QY
  Tele 0131 475 2372
  Advice, support and refuge to women who have been abused mentally, physically or sexually. Provides contact information for all local Women's Aid groups throughout Lothian.
- Space 44, 44 Montrose Terrace, Edinburgh EH7 5DL
  Tele 0131 652 0999
  Advice, information, support and advocacy for women. Offers drop-in and crèche facilities.
- Domestic abuse freephone helpline (10am – 12 midnight)
  Tele 0800 027 1234

Homelessness

- The Access Point (including the Edinburgh Homeless Practice)
  17 Leith Street, Edinburgh EH1 3AT
  Housing, Social Work and Health care services for homeless people.
  Tele 0131 529 7747
- Streetwork, 14 Albany Street, Edinburgh EH1 3QB
  Tele 0131 476 3666
  Support, practical help and advocacy for homeless people.
- Homeless Outreach Project (HOP), 1A Grindlay Street Court, Edinburgh EH3 9AR.
  Tele 0131 221 9099
- Shelterline - Freephone number
  Information on emergency access to refuge services and general housing matters.
  Tele 0808 800 4444

Further information

Further help, information, useful addresses, websites

All pregnant women in Lothian are given a copy of the NHS Health Scotland (formerly HEBS) book '***Ready Steady Baby***'.
Please refer to pages 151-155 for a list of helpful contacts.

Also refer to the Health Promotion Library Scotland, The Priory, Canaan Lane, Edinburgh EH10 4SG. Tele 0845 912 5442. www.hebs.com/library

Staff can also access the Library and Resource Centre, Lothian NHS Board, Deaconess House, 148 Pleasance, Edinburgh.
Tele 0131 536 9451

Pregnancy, childbirth, breastfeeding and child care

- NHS Health Scotland,
  Woodburn House, Canaan Lane, Edinburgh EH10 4SG.
  Tele 0131 536 5500
  www.hebs.org
  (2003) '*Ready Steady Baby*'
  (1995) '*The Breastfeeding Facts Pack*'
- National Childbirth Trust (NCT),
  Alexandra House, Oldham Terrace, London
  Tele 0870 444 8707
  Breastfeeding helpline (Tele 0870 444 8708)
  www.nctpregnancyandbabycare.com
- Lawrence RA. (1999) '*Breastfeeding: A Guide for the Medical Profession*', 5th Edition, Mosby, St Louis.
- SANDS (Stillbirth and Neonatal Death Society)
  Tele 0131 622 6263
- Scottish Cot Death Trust,
  Royal Hospital for Sick Children, Glasgow G3 8SJ.
  Tele 0141 357 3946
  www.gla.ac.uk/departments/childhealth/SCDT/
- Lothian Health Council, 21 Torphichen Street, Edinburgh
  (2000) '*Women's Views of Maternity Services in Lothian*'
  Tele 0131 229 6605
  www.lhc-online.org

- Royal College of Obstetricians and Gynaecologists (RCOG)
  Guidelines on good practice
  www.rcog.org.uk
- Department of Child & Adolescent Health and Development (CAH),
  World Health Organisation, Geneva, Switzerland.
  www.who.int/child-adolescent-health
- Royal College of Psychiatrists
  Helpful leaflets & fact sheets on all aspects of mental health e.g.
  '*Postnatal depression – Help is at hand*'
  www.rcpsych.ac.uk/

Smoking, alcohol and drugs

- National Drugs Helpline
  Tele 0800 776600
- Scottish Drugs Forum (SDF),
  Shaftsbury House, 5 Waterloo Street, Glasgow G2 6AY.
  Tele 0141 221 1175
  www.sdf.org.uk
- DrugScope, 32 Loman Street, London SE1 0EE
  Tele 020 7928 1211
  www.drugscope.org.uk
- ISD (Scotland)
  www.drugmisuse.isdscotland.org
- Substance Misuse Management in General Practice
  www.smmgp.demon.co.uk
- National Treatment Agency for Substance Misuse
  www.nta.nhs.uk
- Exchange: Tools for Harm Reduction
  www.exchangesupplies.org
- Alcohol Focus Scotland (formally the Scottish Council on Alcohol),
  166 Buchanan Street, Glasgow G1 2NH.
  Tele 0141 572 6700
  www.alcohol-focus-scotland.org.uk
- Drinkwise, 2nd Floor, 166 Buchanan Street, Glasgow G1 2LW
  Tele 0141 572 6704
  www.drinkwise.co.uk

- Alcohol Concern,
  Waterbridge House, 32-36 Loman Street, London SE1 0EE.
  Tele 0207 922 8667
  www.alcoholconcern.org.uk
- Alcoholics Anonymous
  National Helpline. Tele 0845 769 7555
  www.aa-uk.org.uk
- Drinkline
  National helpline. Tele 0800 917 8282
- Down Your Drink
  Online programme for reducing drinking.
  www.downyourdrink.org
- ASH Scotland, 8 Fredrick Street, Edinburgh EH2 2HB.
  Tele 225 4725
  www.ashscotland.org.uk
- Smokeline
  A free helpline for people who want to give up smoking.
  Tele 0800 848484
- Children's Liver Disease Foundation
  www.childliverdisease.org
- British Liver Trust, Ransomes Europark, Ipswich, England IP3 9QG.
  Tele 01473 276326
  www.britishlivertrust.org.uk
- Hepatitis C information site (prepared by NHS based doctors & nurses)
  www.hepc.org.uk
- National AIDS Helpline (24 hours)
  0800 567 123
- British HIV Association (BHIVA)
  www.bhiva.org
- Hepatitis C Resource Pack (NHS Lothian)
  Free pack containing information leaflets for patients as well as the *Hepatitis C test proforma* to guide pre and post test discussion with patients.
  Copies available from the Library and Resource Centre, Deaconess House, 148 Pleasance, Edinburgh EH8 9RS. Tele 0131 536 9451
  Also available on NHS Lothian website www.nhslothian.scot.nhs.uk

General

- Scottish Executive website
  www.scotland.gov.uk
- Scottish Health website
  www.show.scot.nhs.uk
- NHS 24
  Tele 08454 242424
  www.nhs24.com
- NHS Helpline
  Gives information about health services on freephone number.
  Tele 0800 224488

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Glossary

Glossary

Antenatal care: care provided by professionals during pregnancy in order to detect, predict, prevent and manage problems in the woman or her unborn child.
APGAR score: score measured at birth by observations of the babies health e.g. colour, tone, heart rate etc.
Benzodiazepines: a class of drugs previously called 'minor tranquillisers' which reduce anxiety and have a sedative effect.
Binge drinking: excessive amount of alcohol taken on any one occasion, usually twice the recommended daily amount (i.e. 6 units or more for women).
Bio-physical profile assessment: use of ultrasound scanning to assess fetal well-being.
Birth plan: a written record of a woman's preferences for her care during pregnancy, labour and childbirth.
Brief intervention: usually consists of a brief assessment of substance use, information and advice on risks associated with substance use and details of local services and other helpful resources.
Caesarean Section: an operation where the baby is delivered through an incision through the abdomen and uterus.
Care Pathways: structured multidisciplinary care plans which detail essential steps in the treatment and care of patients with a specific illness or condition.
Child Protection Case Conference: a multi-disciplinary meeting convened by Social Work to assess the level of risk to children and to decide on what action needs to be taken, if any.
CNS depressant: a drug which acts on the central nervous system to suppress neural activity in the brain e.g. opioids and benzodiazepines.
CNS stimulant: a drug which acts on the central nervous system to increase neural activity in the brain e.g. amphetamines, cocaine, nicotine.
Conception: the act of becoming pregnant.
Congenital abnormalities: an anomaly present at birth.
Continuity of care: a situation where all professionals involved in delivery of care share common ways of working and a common philosophy so that the woman does not experience conflicting experience or advice.
Detoxification: process by which a user withdraws from the effects of alcohol or drugs over a short period of time (i.e. 1 to 3 weeks), usually managed with medication.
Deprivation category: the Carstairs and Morris index is composed of 4 indicators judged to represent material disadvantage in the population. These include: overcrowding, male unemployment, social class 4 or 5 and no car.
Drug/Alcohol Dependence: a syndrome characterised by a cluster of signs and symptoms including physical dependence (e.g. tolerance and withdrawal) and psychological dependence (e.g. compulsion, avoidance behaviour, disregard for harm).

Drug/Alcohol related problem: refers to a whole spectrum of harm (physical, psychological, social) associated with substance use.
Fetal: of the fetus or unborn child.
Gestation: age of fetus since conception.
'High Risk' pregnancy: pregnancy with increased likelihood of complications, usually managed by obstetrician.
Harmful drinking: levels of drinking which cause physical or psychological harm
Injecting paraphernalia: all the equipment used for injecting drugs e.g. spoon, filter etc
Intoxication: a state where the individual has drunk or taken drugs sufficient to significantly impair functions such as speech, thinking, or ability to walk or drive.
Intrapartum care: care provided during labour and childbirth.
Intrauterine growth restriction (IUGR): previously known as intrauterine growth retardation.
In-utero: in the uterus or womb, unborn.
Lead professional: the professional who will give a substantial part of the care personally and who is responsible for ensuring that the woman has access to care from other professionals as appropriate.
LHCC: Local Health Care Co-operative, soon to be replaced by 'Community Health Partnerships'.
'Low risk' pregnancy: normal pregnancy with few anticipated complications, usually managed by midwife
Midwifery team: a small team of midwives (normally based in the community) who share responsibility for care during pregnancy, childbirth and the postnatal period.
Neonatal period: first 28 days of a baby's life.
Obstetric: the branch of medicine and surgery that deals with pregnancy and childbirth.
Opiates: drugs derived from the opium poppy e.g. morphine, codeine.
Opioids: includes both opiates and their synthetic analogues e.g. methadone, dihydrocodeine, pethidine.
Parity: the number of maternities to a woman (children born live or stillbirth after 24 weeks gestation).
Postnatal: after the birth.
Postpartum care: care provided in the period following delivery.
Polydrug use: the use of more than one drug at a time.
Pre-term: premature baby born before 37 weeks gestation (a 'full-term' pregnancy lasts 40 weeks).
Problem drug/alcohol use: tends to refer to drug use (dependent or recreational) which causes social, financial, health or legal problems.
Recreational drug use: the occasional use of drugs for pleasure or leisure.
Reproductive health: health of the organs involved in the process of conception, pregnancy and childbirth.

Resuscitation: revival of someone who is in cardiac or respiratory failure or shock.
Screening: mass examination of the population to detect specific illnesses or conditions.
Shared care: an agreed arrangement between a GP and an obstetrician / midwife / paediatrician / or other health specialist over care for a woman.
Social Inclusion: ensuring that everyone regardless of sex, wealth, race, religion, age, lifestyle and geographical position has the opportunity to live full and active lives free from injustice, discrimination and poverty.
Stillbirth: baby born dead after 24 completed weeks of pregnancy. Stillbirths must be registered and the cause of death established before a certificate of stillbirth can be issued and a burial take place.
Substance misuse: taken to mean the use of drugs or alcohol in a socially unacceptable, hazardous or harmful way.
Teratogenic: causing fetal malformations or congenital birth defects.
Tolerance: higher doses of drug are needed to maintain the same effect.
Trimester: each period of three months in pregnancy (1st, 2nd and 3rd trimesters).
Ultrasound scan: image created by use of sound waves, which can confirm pregnancy and determine fetal size and well-being.
Umbilical artery Doppler: is a fetal monitoring assessment test.
Vertical transmission: transmission from mother to baby either in utero, during childbirth or through breastfeeding.
Viral load: the amount of virus circulating in the blood.
Volatile substances: refers to solvents and inhalants including aerosols.
Withdrawal: the body's reaction to the sudden absence of alcohol or a drug to which it has adapted.

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Appendix 1:
Blood Borne Viruses

Blood Borne Viruses and Pregnancy

HIV, hepatitis B and hepatitis C are all blood borne viruses (BBV) that can be passed from mother-to-baby (vertical transmission).

Antenatal testing for HIV, HBV, HCV

In Lothian, testing for HIV and hepatitis B has been part of *routine antenatal screening* since December 1999. Testing for hepatitis C can be offered to those at risk, but is *not* part of the routine screening programme. The aim of testing women in pregnancy is to reduce the likelihood of mother-to-baby transmission and to improve and protect the health of both mother and baby.

All pregnant women in Lothian receive a copy of the leaflet '*A Guide to Routine Blood Tests Offered During Pregnancy'* (NHS Health Scotland 2003). At the *booking appointment* the midwife should ask the pregnant woman whether she has understood the leaflet. The reasons for antenatal screening and the benefits of each test are briefly discussed before *informed consent* is obtained. All tests are carried out unless the women specifically requests otherwise. Women can '*opt out'* of any test, if they wish. The 'opt out' rate for the HIV and hepatitis B tests in Lothian is very low (<5%).

All ***negative*** results are communicated to the woman at her next antenatal appointment. Negative results are recorded in the woman's '*hand held*' records.

If an HIV antibody or Hepatitis B (HBsAg) test is ***positive*** the virologist reports the results in confidence to the designated lead Obstetrician and Midwife responsible for Blood Borne Viruses. The obstetrician/midwife recalls the woman so that she can be given the results in person and to retest. At this visit, support, treatment and care are discussed.

HIV (Human Immunodeficiency Virus)

HIV is the virus that causes AIDS (Acquired Immune Deficiency Syndrome). HIV can be passed from mother to baby during pregnancy (intrauterine), childbirth (intrapartum) and breastfeeding. The risk of transmission is related to maternal health, obstetric factors and infant

prematurity (BHIVA 2001). The majority of vertical transmission occurs during the intrapartum period. There is a close correlation between maternal viral load and risk of transmission: the higher the viral load the greater risk of transmission. Breastfeeding is also an important route of transmission. The additional risk of transmission through breastfeeding, over and above the intrauterine and intrapartum contribution, is estimated to be between 7-22% (BHIVA 2001).

Without treatment, the transmission rate is approximately 15%-25%. The prevalence of HIV among pregnant women in Scotland has increased recently. In 2002, unlinked anonymous testing found a prevalence of 5.8 per 10,000 population (SCIEH 2003). Without treatment, HIV-infected children develop chronic disease and about 20% develop AIDS or die in the first year of life. By the age of 6 years, about 25% will have died and most surviving children will have some illness because of their infection. The long-term picture is unknown, but all children with HIV benefit from early life-prolonging treatment (Scottish Executive 2002).

The *aim* of the antenatal screening programme is to reduce the number of babies born with HIV and to improve the health of infected women and their babies. Diagnosis in pregnancy means that women can be offered advice, treatment and interventions to reduce the likelihood of mother-to-baby (vertical) transmission of the virus. If appropriate interventions are accepted, the risk of vertical transmission can be reduced to below 2%.

The recommended interventions are set out in the British HIV Association (BHIVA) '*Guidelines for the management of HIV infection in pregnant women and the prevention of mother-to-child transmission*' (2001).

Interventions include:

- ✓ The use of antiretroviral drugs for both mother and baby
- ✓ Careful obstetric management during pregnancy and delivery
- ✓ Delivery by pre-labour caesarean section
- ✓ Bottle feeding

An expanded version of the BHIVA guidelines, with an appendix on safety and toxicity data is available on the BHIVA website: www.bhiva.org

Management of HIV positive pregnant women

The care offered to HIV positive pregnant women in Lothian is jointly managed by specialists from Midwifery, Obstetrics, HIV, Paediatrics, Primary Care and other services (e.g. social work, drug and HIV services). Health care staff should refer to the agreed *management protocol* and care pathway. The approach to treatment is *individualised*, according to the needs and choices of each mother. Good liaison is required between all professionals to ensure that the pregnancy and birth plan proceed appropriately and that the views and wishes of the woman are respected.

There are *two scenarios* in which HIV infection may be identified during pregnancy. The first is where HIV infection is diagnosed during pregnancy, normally at the antenatal clinic. The second is where a known HIV positive woman falls pregnant.

Antiretroviral drug therapy (ART) for the mother aims to reduce her viral load to '*undetectable*'. ART is given according to the mother's HIV health status. Normally it is avoided in the 1st trimester. If possible, treatment will be deferred until just before the 3rd trimester (20-24 weeks) in order to reduce fetal exposure. Women who become pregnant whilst taking ART that is successfully suppressing viral load, will normally continue with their ART throughout pregnancy.

The recommended *mode of delivery* is also dependent on viral load. Caesarean section is recommended if the viral load result is >1000. If the viral load is <1000 (ideally <50 copies /ml) at term then vaginal delivery is considered an acceptable choice for the mother. The choice should be discussed with the mother. If a woman chooses to breastfeed despite the evidence (perhaps because of cultural reasons), then she should be advised to breastfeed exclusively. Exclusive breastfeeding has been shown to be safer than mixed breast and bottle feeding.

Antiretroviral drug therapy (ART) is normally given to the baby for the first 4 weeks. The paediatrician determines the choice of ART. Most neonates born to mothers known to have HIV will be exposed to ART *in utero*. The possible adverse effects of ART to the fetus and developing child continue to be monitored. All women who receive ART in pregnancy are registered with the International Drug Registry and exposed infants

are followed up for at least 1 year. Dr Jacqueline Mok, (Community Paediatrician at the Royal Hospital for Sick Children), is responsible for the follow-up of all babies born to HIV positive mothers in Lothian. To date, no increased risk of birth defects or growth problems have been documented with AZT. However, much less is known about the safety of other anti-HIV drugs. All babies who have been exposed to ART are reported to the British Paediatric Surveillance Unit.

Dr Mok undertakes *diagnosis* of HIV infection in *infants* born to HIV positive mothers. All babies born to mothers infected with HIV will test HIV-antibody positive at birth due to the presence of *maternal* HIV antibodies. Babies who are not infected will become HIV antibody negative by 18 months of age. Other tests (using PCR techniques) are used to diagnose children by the age of 3 months.

All professionals supporting HIV infected pregnant women should be aware of the *psychosocial* issues that can impact on HIV treatment and care (BHIVA 2001). Women may need considerable help and support to come to terms with the implications of their diagnosis and the management of their infection.

Hepatitis B (HBV)

Hepatitis B is a virus which affects the liver and is highly infectious. It can be passed from mother to baby during childbirth (approximately 80%-90% transmission rate from infectious 'carrier' mothers). People who remain *chronically* infected with hepatitis B (i.e. 'carriers') can remain well for many years and may not know they are infected. Babies who are infected are at risk of developing serious liver disease later in life.

Preventing HBV infection

The high rate of mother-to-baby transmission can be ***largely prevented through immunisation***. If the antenatal hepatitis B surface antigen test is positive, a vaccination programme is started at birth to enable the baby to develop immunity and to have a healthy life. The midwife delivering intrapartum care notifies the neonatal Paediatrician that the woman is in labour and ensures that the medications for the baby are in stock. Within 12 hours of birth the baby receives *immunoglobulin* (which neutralises the virus) and the first *vaccine dose* in the postnatal ward. The baby can be

breast fed after these are given. The *second* dose of vaccine is given at 1 month, *third* dose at 2 months and *fourth* dose at 12 months. Immunity checks are carried out at 14 months of age. The GP and Health Visitor are informed, as they are responsible for ensuring that the baby receives all the vaccines to complete the immunisation programme. The SIRS (Scottish Immunisation Recall System) database is notified to alert staff that administration of the vaccine is due. When the mother leaves hospital with her baby she is given a *hepatitis B vaccination record* card. Health care staff should refer to the '*Management of Hepatitis B in Pregnancy'* protocol (available from Public Health).

The *Health Protection Team* (Public Health) are also informed about any person with hepatitis B infection (HBsAg positive), as it is important to trace contacts. Sexual partners, children and other household contacts are offered testing and immunisation where appropriate.

The *Centre for Liver and Digestive Disorders* (CLDD) at the Royal Infirmary of Edinburgh (RIE) offers a service for patients who are chronic hepatitis B carriers (defined as those who are HBsAg positive for 6 months or more). Newly diagnosed patients can also be referred to the *Regional Infectious Diseases Unit* (RIDU) for assessment.

Drug use and hepatitis B

It is ***good practice*** to offer all women with a *history of injecting drug use* (or a sexual partner with a history of drug use) full screening for HBV in pregnancy (i.e. the *Ab* test in addition to the *Ag* test). Women with no prior infection with HBV can be safely immunised during pregnancy (Scottish Executive 2003). Current sexual partners and existing children can also be immunised. Hepatitis B and Hepatitis A immunisation is recommended for any Hepatitis C positive or HIV positive woman (Scott 2003).

General Practitioners, Midwives, Health Visitors and drug workers are all in a good position to raise the subject of Hepatitis B, and to recommend screening and immunisation. Immunisation can now be easily carried out in General Practice.

Hepatitis C (HCV)

Hepatitis C is a virus, which affects the liver and can be passed from mother to baby, either during pregnancy or childbirth, but *not* through breast feeding. The transmission rate is thought to be low (below 5%). People who are *chronically* infected with hepatitis C can remain well for many years and may not know they are infected. Babies who are infected are at risk of developing serious liver disease later in life. Unfortunately, there is *no vaccine* currently available for hepatitis C. Combination therapy drug treatment for hepatitis C (interferon alpha & ribavirin) is *contraindicated* during pregnancy and breastfeeding (because of foetotoxic and teratogenic effects) and in *young babies and children*. As yet, there are no proven interventions to prevent or reduce the risk of vertical transmission (except in the case of co-infection, see below). ***Breast feeding is encouraged*** as there is no evidence that HCV can be transmitted by this route. Universal screening of all pregnant women is therefore not recommended.

Identifying hepatitis C infection in pregnancy is still useful however, for a number of reasons:

- ✓ the woman's health can be monitored
- ✓ she can be given healthy lifestyle advice
- ✓ she can be given advice to prevent further risk of exposure
- ✓ she can be immunised against hepatitis B and hepatitis A
- ✓ she can be given information on infection control in the home and elsewhere
- ✓ she can be referred for specialist treatment once the baby is delivered.

Antenatal testing is also useful because infected babies can be identified, they can be immunised against hepatitis B and their paediatric care can be managed appropriately. Dr Jacqueline Mok, Paediatrician at RHSC, is part of the European paediatric Hepatitis C Network and will see all infants born to mothers with HCV. Infants are monitored for signs and symptoms of hepatitis C during the first year of life. Blood tests are also carried out using PCR techniques.

It is ***good practice*** therefore to offer the test to all pregnant women *at risk of HCV* infection.

Risk factors for HCV include:

- ✓ History of intravenous drug use, HIV or HBV infection
- ✓ Recipients of blood or blood products prior to 1991
- ✓ Sexual partner with a history of injecting drug use
- ✓ Sexual partner known to have either HIV, HCV or HBV infection
- ✓ Unsterile body piercing, tattoos, acupuncture etc
- ✓ Unsterile medical or dental procedures abroad

Because testing for HCV during pregnancy is not part of routine screening, the midwife may want to refer the woman to her General Practitioner or other HCV testing site. All staff offering the test for HCV should follow the agreed testing procedure - see the '*Hepatitis C Test Proforma*', which is included in the *Hepatitis C Resource Pack* (Lothian Health 2002).

Mothers found to be HCV (PCR positive) are referred for specialist care by Obstetric, Paediatric and CLDD (Liver Unit) staff. *Capital C* is a voluntary organisation that offers support to people affected by hepatitis C (see *'services list'* for further details). The *Children's Liver Disease Foundation* is an organisation that specialises in supporting children with liver disease (www.childliverdisease.org)

Co-infection (HIV & hepatitis)

Co-infection with HIV, HCV and HBV can occur due to shared routes of transmission. Caesarean section reduces mother-to-baby transmission of HCV in mothers co-infected with HIV. C-section is therefore recommended even if there is no indication for a C-section related to HIV. Drug treatment for HIV disease does not affect the transmission of HCV.

Ideally, all women at risk of blood borne viruses should be offered testing *before* they conceive. See *services list* for further information on available testing sites.

Health Care staff with a special interest in Blood Borne Viruses and Pregnancy

There are a number of health care staff who have a special role in the management of pregnant women with blood borne viruses in Lothian. These include:

- Dr Wang Liston (Obstetrician and Gynaecologist) and Fiona McNeilage (Midwife) follow up all positive women attending Simpson Centre for Reproductive Health at the Royal Infirmary of Edinburgh.
- Dr Gerry Beattie (Obstetrician and Gynaecologist) and Fiona McGuckin (Community Midwife) follow up all positive women in West Lothian at St John's Hospital.
- Dr Jacqueline Mok (Paediatrician) at the Royal Hospital for Sick Children cares for all babies born to infected mothers.

Appendix 2:
Link Midwives
(Substance Misuse)

Link Midwives and Nurses (Substance Misuse)

Simpson Centre for Reproductive Health, Royal Infirmary of Edinburgh, Edinburgh EH16 4SA

Hospital staff

Antenatal Clinic	*Fiona McNeilage* (co-ordinator for link midwives/nurses)	Tel. 242 2546 (22546)
Neonatal Unit	*Angela Greco* & *Jane Anderson*	Tel. 242 2601 (22601)
Postnatal Ward	*Fatima Goulter*	Tel. 242 1191 (21191)
Labour Ward	*Gillian Fordyce*	Tel. 242 2542 (22542)

Community midwifery staff

East Lothian	*Linda Coull* Community Midwives Office, Roodlands Hospital, Haddington EH41 3PF	536 8304
Midlothian	*Alison Bagan* Community Midwives Office, Bonnyrigg Health Centre, 35-37 High Street, Bonnyrigg, EH19 4DA	536 8949
South-West Edinburgh	*Claire Stephen* Community Midwives Office, Sighthill Health Centre, Calder Road, Edinburgh EH11 4AU	537 7116
North-East Edinburgh	*Louise Croan* & *Gillian Reid* Community Midwives Office, Eastern General Hospital, Seafield Road, Edinburgh EH6 7LN	536 7345
North-West Edinburgh	*Jill Kelly* Community Midwives Office, Pennywell Resource Centre, 31-33 Pennywell Road, Edinburgh, EH4 4PJ	537 4251
North-West Edinburgh	*Katy Ruggeri* Community Midwives Office, North Lodge, Corstorphine Hospital, 136 Corstorphine Road, Edinburgh EH12 6TT	459 7257
South-East Edinburgh	*Pauline Connolly* Community Midwives Office, Craigmillar Medical Centre, 106 Niddrie Mains Road, Edinburgh, EH16 4DT	536 9630
South Central Edinburgh	*Romana Shillinglaw* Community Midwives Office, Tollcross Health Centre, Ponton Street, Edinburgh EH3 9QQ	536 9847

Maternity Unit, St John's Hospital, Livingston, West Lothian

Deborah Stewart & *Ruth Batten*	Special Care Baby Unit, St John's Hospital, Livingston	01506 419666 ext 3097

Community midwifery

Fiona McGuckin	Whitburn Health Centre, 1 Weaver's Lane, Whitburn, West Lothian, EH47 0SD	01501 740719/297 Mobile: 07740 841769

Appendix 3:
Link Health Visitors (Substance Misuse)

Link Health Visitors (Substance Misuse)

South West Edinburgh LHCC	***Telephone no.***
Val Waters & Fiona Bruce Whinpark Surgery, 6 Saughton Road, Edinburgh, EH11 3RA	455 5299
South East Edinburgh LHCC	
Wilma Laird Howdenhall Surgery, 57 Howdenhall Road, Edinburgh, EH16 6PL	664 1004
Lisa Miller Southern Medical Centre, 322 Gilmerton Road, Edinburgh, EH17 7PR	672 1168
Margo Hayes Craigmillar Medical Centre, 106 Niddrie Mains Rd, Edinburgh, EH16 4DT	536 9620
South Central Edinburgh LHCC	
Linda Hornby 32 Lauriston Place, Edinburgh EH3 9EZ	228 5873
Dee Mills Springwell Medical Centre, Ardmillan Terrace, Edinburgh, EH11 2JL	537 7451
North West Edinburgh LHCC	
Jane Henry Crewe Medical Centre, 135 Boswall Parkway, Edinburgh, EH5 2LY	552 1320
North East Edinburgh LHCC	
Jane Jackson & Louise Ferguson Bellevue Medical Centre, 26 Huntingdon Place, Edinburgh EH7 4AT	557 6585
East Lothian	
Margaret St Clair Gunn Prestonpans Health Centre, Preston Road, Prestonpans, East Lothian EH32 9QS	01875 812979
Midlothian	
Gillian Robertson & Anne MacDonald Dalkeith Medical Centre, St Andrew Street, Dalkeith, Mid Lothian EH22 1AP	561 5510
West Lothian	
Susan Bell Murraygate Children's Centre, 88 Murraygate Industrial Estate, Whitburn, West Lothian EH47 0LE	01501 742388
Liz Henderson Ashgrove Health Centre, Blackburn, West Lothian EH47 7LL	01506 654965

Appendix 4:
Model Care Pathway

MODEL CARE PATHWAY: SUBSTANCE MISUSE IN PREGNANCY

Pre-conceptual Care

- ✓ Advice on reproductive health and contraception
- ✓ Advice on sexual health
- ✓ Advice on pregnancy care

Confirmation of pregnancy

- ✓ 'Ready Steady Baby' book
- ✓ Woman to attend GP (e.g. health advice & folic acid)
- ✓ Refer to Midwifery Team
- ✓ Arrange scan

12 weeks… **Booking appointment**

Multidisciplinary Assessment

- ✓ Follow antenatal 'Care Pathway'
- ✓ Assessment of drug use (including tobacco and alcohol)
- ✓ T-ACE (alcohol questionnaire)
- ✓ Antenatal Liaison Form (Substance Misuse)
- ✓ Leaflet *'Pregnant… and using alcohol or drugs?'*
- ✓ Refer to drug/alcohol specialist
- ✓ Blood Borne Virus testing – if positive, follow agreed protocol
- ✓ Risk assessment
- ✓ Commence 'infant feeding' checklist
- ✓ Consent form for multidisciplinary / multi-agency working
- ✓ If woman does not attend booking – follow-up by Midwife

16 weeks… **Antenatal appointment**

Implement care plan

- ✓ Discuss and agree care plan
- ✓ Discuss and agree management of drug/alcohol use
- ✓ Identify 'lead professional' / 'care co-ordinator'
- ✓ Give handheld records

22 weeks… **Antenatal appointment**

- ✓ Monitor drug/alcohol use
- ✓ Monitor progress of care

28 weeks… **Antenatal appointment**

Review care plan

- ✓ Case discussion / care plan review meeting
- ✓ Reassess social circumstances / risk
- ✓ Discuss breastfeeding
- ✓ Growth scan / fetal monitoring

32 weeks… **Antenatal appointment**

- ✓ Start preparation for parenthood
- ✓ Discuss birth plan
- ✓ Discuss NAS and give parent information leaflet
- ✓ Child protection case conference (if needed)

36 weeks… **Antenatal appointment**

- ✓ Preparation for parenthood
- ✓ Assess fetal growth
- ✓ Discuss labour and delivery (include protocol re prescription)

38 weeks… **Antenatal appointment**

- ✓ Preparation for parenthood
- ✓ Monitor drug/alcohol use – update antenatal liaison form

Term…
(40 weeks) **Childbirth**

- ✓ Pregnancy outcome liaison form
- ✓ Neonatal Abstinence Syndrome (NAS) assessment and care
- ✓ Discharge plan (include prescription arrangements)
- ✓ Discharge pack – discuss info on SIDS (cot death)
- ✓ Follow postnatal 'Care Pathway'

10 days… **Postnatal care**

Review care plan

- ✓ Continue multidisciplinary support / postnatal care plan
- ✓ Continue NAS assessment and care (if required)
- ✓ Monitor drug / alcohol use
- ✓ Relapse prevention support
- ✓ Midwife ends care (day 10 to 28)
- ✓ Home visit by Health Visitor

Appendix 5: Consent form for multi-disciplinary working

Consent Form for Multi-disciplinary / Multi-agency Working

Please read the following information before you sign this form.

A number of different professionals and organisations may be involved in your care. To provide you with the best possible care and support we need to work together.

Normally we find it useful to share relevant information with each other and to ask each other for advice when we need it. We also need to agree a common 'care plan' with you and keep each other informed about the progress you are making. We also want to make sure that we don't duplicate each others work, give you conflicting advice, or miss out on providing you with something that you might need.

Each different organisation has its own policy on confidentiality and keeps separate written records. Confidentiality can only be breached in exceptional circumstances so we need your consent before we can pass information to professionals who work in other organisations. If you complete this form you will be giving us permission to do this.

I give my permission for the following professionals and organisations to share information regarding my care.

Name:
Organisation:

Name:
Organisation:

Name:
Organisation:

Name:
Organisation:

Name:
Organisation:

Name of client: ……

Address: ……

Date of Birth: ……

Signature: ……

Date consent form signed: ……

Appendix 6:
GP allocation letter

The Administrator, Lothian Health
Primary Care Services
Stevenson House
555 Gorgie Road
Edinburgh, EH11 3LG

Date:

Dear Sir/Madam,

I am having difficulty in registering with a doctor. Could you please allocate me a GP as soon as possible.

I have detailed my particulars below.

Name: …….

Address: ……

……

Date of Birth:……

Place of Birth:……

Last GP: ……

Address: ……

Thank you.

Yours sincerely,

Appendix 7:
T-ACE alcohol screening questionnaire

Antenatal screening questionnaire

Alcohol use in pregnancy

T-ACE

T (tolerance) How many drinks does it take to make you feel high?

Answer: *'3 drinks or more'* scores 2 points

A (annoyance) Have people annoyed you by criticising your drinking?

Answer: '*Yes'* scores 1 point

C (cut down) Have you ever felt you ought to cut down your drinking?

Answer: '*Yes'* scores 1 point

E (eye-opener) Have you ever had a drink first thing in the morning to steady your nerves or to get rid of a hangover?

Answer: '*Yes'* scores 1 point

Total Score _____

Date of test _____

Lowest score possible = 0
Highest score possible = 5

A total score of *two points or more* will correctly identify most women whose drinking is hazardous, harmful or dependent.

See guidance on how to respond in '*Substance Misuse in Pregnancy: A Resource Pack for Professionals in Lothian'*.

Appendix 8:
Drug & Alcohol Diary

Drug and Alcohol Diary

Day	Times	Type of drug/drink taken	Amount taken	Where? Why? Effects?

Name: **Date:**

Appendix 9:
Midwifery Liaison Forms (Substance Misuse)

NHS Lothian

Antenatal Liaison Form (Substance Misuse) **SM103**

Mother's name: .....
Date of birth: .....
Address: .....
Tele. .....

✂----------✂

Postcode: EH _ _ / _ (only 1st number of 2nd part) **Hospital Unit No** .....

Mother's age:..... **Mother's Chi No**. .....

E.D.D: ..... Parity: .....

	Tele. No.
GP:	.....
Midwife:	.....
Health Visitor:	.....
CDPS / APS worker:	.....
Other drug / alcohol worker:	.....
Social Worker:	.....
Maternity Unit:	.....
Consultant Obstetrician:	.....

Smoker?... Yes/No If yes, number per day? .....

Prescribed medication at booking (drugs & dosage)

.....

.....

Dispensing Arrangements?.....
Pharmacy? ..... Tele: .....
Name of Prescriber? ..... Tele: .....

Injecting drug use during pregnancy?... Yes/No If yes, please detail frequency .....
If no, ever injected drugs in the past?... Yes/No

Illicit (street) drug use since conception?
(all drugs used, excluding those prescribed, enter average daily amounts taken in 1st trimester)

Heroin	Diazepam/Temazepam .....
Dihydrocodeine	Other tranquillizers? .....
Methadone	Amphetamines ('speed') .....
Other opiates?.....	Cocaine / Crack .....
Cannabis	Ecstasy .....

Solvents / Volatile substances .....
Other drug use? .....

Referred to **Community Drug Problem Service (CDPS)**?... Yes/No Attended?... Yes/No
Outcome? .....

NHS Lothian

Alcohol use (tick average weekly consumption in 1st trimester)?

0-14 units ❑ 15-21 units ❑ 22-28 units ❑ 29-35 units ❑ 36-42 units ❑ over 42 units ❑

Pattern of alcohol use? (daily use?, weekend use? binge drinking? etc) .....
.....

Referred to **Alcohol Problems Service (APS)**? ... Yes/No Attended? ... Yes/No
Outcome? .....

History of drug/alcohol misuse in any **previous pregnancies**?... Yes/No
If yes, **outcome** of previous pregnancies?.....
.....

Additional concerns? (e.g. not registered with GP, homeless, mental health problems, debts, legal problems, literacy problems, relationship difficulties, domestic abuse, sex industry worker etc)
.....
.....
.....
.....

Child care concerns?... Yes/No Pre-birth child protection case conference held?... Yes/No

Antenatal testing for **Blood Borne Viruses**?

HIV	-	test accepted/declined	
Hepatitis B	-	test accepted/declined	HBV immunised? ... Yes/No
Hepatitis C	-	test offered?... Yes/No	If yes, accepted/declined?

Referred to **high risk** clinic?... Yes/No If yes, attended?... Yes/No

Date of antenatal **case discussion** (around 28th week): .....
Professionals involved?.....

Drug / alcohol use of **partner**? (please detail illicit & prescribed drugs taken / alcohol units per wk)
.....
.....

Partner's HIV / hepatitis B / hepatitis C status (if known) .....
.....

Date form completed: .....

Signature of key midwife: .....

Later changes to prescribed drugs? (record any medication/dose changes and date of change)
.....
.....
.....

Completed by: .....

***Form SM103. Photocopy and send to Link Midwife (Substance Misuse).**

NHS Lothian

Pregnancy Outcome Form (Substance Misuse) SM203

Mother's name: ..... Mother's d.o.b.: .....
Baby's name: .....
Address: .....

✂----------✂

Postcode: EH _ _ / _ (only 1st number of 2nd part) **Mother's Unit No** .....

Baby's SM number:..... **Mother's Chi No.**:.....

Delivery date: ..... **Baby's Chi No.**:.....

Gestation: ..... APGARs: .....
Birth weight: ..... Cord pH: .....
Birth length: ..... Head Circumference: .....

Labour ward (please give details… if none state 'none')

Complications in labour? .....
Pain relief during labour? .....
Mode of delivery? .....
Complications of delivery? .....
Problems at birth? .....

Postnatal ward

Baby stayed for 72 hours observation?… Yes/No
Neonatal withdrawal symptoms developed within 72 hours?… Yes/No
If yes, severity… Mild /Moderate/ Severe
Drug treatment administered? .....
Medication on discharge? .....
Breast or bottle feeding on discharge? .....
Other comments? .....
Postnatal ward discharge date: .....
If mother HIV/Hepatitis C positive, baby referred for follow-up?...Yes/No Bloods taken? Yes/No

Neonatal Unit (RIE) / SCBU (West Lothian)

Admission date: .....
Reason for admission: .....
Neonatal withdrawal symptoms? None / Mild / Moderate /Severe
Drug treatment administered? .....
Medication on discharge?.....
Breast or bottle feeding on discharge?.....
Other comments? .....
Neonatal Unit / SCBU discharge date: .....
Toxicology Result: .....

Community

Baby developed NAS symptoms **after** discharge from hospital?… Yes/No

Baby readmitted?… Neonatal Unit, RIE ❑ SCBU, St John's ❑

RHSC ❑ St John's Children's Ward ❑

Date of readmission: ……

Infant feeding at day 10?… Breast fed / Bottle fed

Continued drug / alcohol use whilst breast feeding? (please detail) ……
……

Date of **postnatal case discussion**: ……

Professionals involved discussion?……
……
……

Decisions made?……
……
……

Child protection case conference held (post birth)?… Yes/No

SIDS? (include details) ……

Age of baby on last midwifery visit? …… days old

Date of last midwifery visit? …….

Name of midwife…….

Details of Health Visitor

Name: ……

Address: ……
……

Tele. ……

Form completed by: ……

Midwifery Team:……

Form completed on (date): ……

***Form SM203. Photocopy form and send to Link Midwife (Substance Misuse) after day 10.**

Appendix 10:
NAS assessment score chart

Neonatal Abstinence Syndrome Assessment Score Chart

Unit no: .....

Name: .....

Date of birth: .....

Birth weight: .....

Gestational age: .....

Please fill in score for each 4 hour period.
Write score for each symptom and add together for total score.
If no symptoms enter score = 0
Insert date at beginning of each day and enter time at the beginning of each 4 hour period e.g.

23/06
2 pm

SCORING
Mild symptoms = 0-5
Moderate symptoms = 6-13
Severe symptoms = 14-21

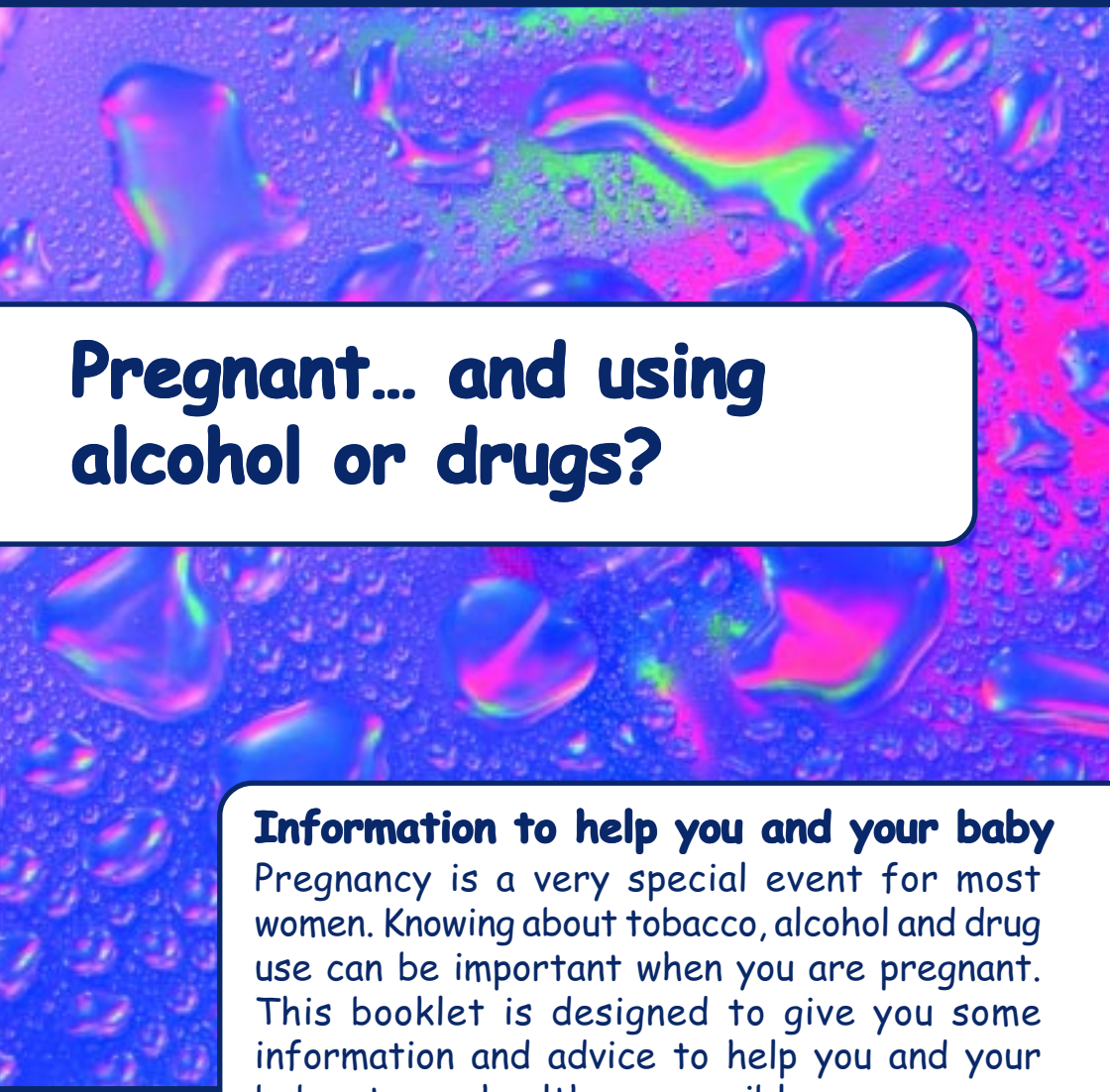
Information for parents...
If baby has a seizure (fit), dial 999 for an ambulance.
If baby has moderate to severe symptoms, seek advice and help from your midwife, GP or hospital.

Date:																		
Time:																		
SYMPTOM:	**SCORE:**																	
Feeding	**Not able to feed at all**	**4**																
	Demands hourly feeds	**2**																
	Feeds very slowly (takes more than 30 minutes)	**2**																
Weight... from Day 7 onwards	**Loss**	**4**																
	Same	**2**																
	Gain	**0**																
Condition of bottom	**Raw/broken skin**	**3**																
	Very red	**2**																
	Mild red	**1**																
Resting/sleeping after feeds	**Less than 1 hour**	**5**																
	1-2 hours	**3**																
	2-3 hours	**1**																
Crying/ irritability	**All the time**	**5**																
	Most of the time	**4**																
	Only some of the time	**1**																
TOTAL SCORE																		

Drug treatment																		
Start time or change dose																		

Comments

NHS Lothian



Pregnant... and using alcohol or drugs?

Information to help you and your baby

Pregnancy is a very special event for most women. Knowing about tobacco, alcohol and drug use can be important when you are pregnant. This booklet is designed to give you some information and advice to help you and your baby stay as healthy as possible.

Drug use in pregnancy

You may be feeling worried about how your drug use might affect your pregnancy and baby. Most women who use drugs and alcohol have a *normal pregnancy and a perfectly healthy baby*. However, there are risks associated with tobacco, alcohol and drug use.

Unfortunately, good evidence on the effects of drug/alcohol use during pregnancy has been difficult to establish. What we do know however, is that *smoking tobacco* in pregnancy is definitely harmful to your baby and can affect your pregnancy in a number of ways. All mothers who smoke should try to give up! Ask your GP, pharmacist or midwife for help.

Using street drugs (like heroin) or being *dependent* on drugs (like methadone or 'valium') can *increase your chances* of having a *premature birth* and a *low birth weight* (small) baby. This in turn can lead to other problems. The risk of *cot death* is also increased, particularly if you smoke tobacco as well.

There is no good evidence to suggest that illicit (street) drugs alone cause congenital birth defects. Heavy *alcohol* use, however, is associated with birth defects and heavy *cocaine* use is associated with a number of problems in pregnancy because the drug reduces blood flow to the developing baby. Street drugs may contain *impurities* and can put extra strain on your liver and kidneys, so it is better if you can use *only prescribed drugs* when you are pregnant.

It is important to remember that there are *many other things* that can affect your pregnancy at least as much as drugs. For instance, the food you eat (your diet), your social circumstances and lifestyle, and whether or not you get good antenatal (maternity) care. Drug use can affect your appetite, weight, dental health, general health, mood and ability to cope with everyday life.

Changing your drug use when pregnant

If you are using opiate drugs (e.g. methadone, heroin or DF118) try to keep your drug use as *stable* as possible throughout your pregnancy. This means taking the same amount of drug every day and avoiding getting 'stoned' or taking extra, as far as you can.

If you experience morning sickness we normally recommend splitting your daily dose into two lots (one dose in the morning and one at night). Splitting up your dose will keep you and your baby more stable late in pregnancy too.

Injecting drugs carries a lot more risks for you and your baby, especially the risk of infections. It is also associated with premature labour and delivery. If you are injecting drugs you will be given help to stop or cut down if you can. If you are dependent on heroin you will be advised to take *prescribed* opiates instead (e.g. methadone). Seek help from drug services… they will see you quickly.

Reducing**……**if you think you could manage to *reduce* your drug use a bit then you would be supported to do so. Talk to your doctor first, so you can do this sensibly. It is important to avoid relapsing when you are reducing, so *slow* reductions are normally recommended. If you are taking benzodiazepines (e.g. 'valium') you will be given help to reduce these first.

Stopping**……**it is generally safe to stop using tobacco, cannabis ('hash'), amphetamines ('speed'), ecstasy, cocaine or 'crack', solvents ('gas' and 'glue'), 'acid' and other 'designer' drugs. We normally suggest stopping all these drugs in pregnancy. If you cannot stop taking *stimulant* drugs (cocaine/'crack' or 'speed') then get help as soon as you can.

Some women who are *dependent* on opiates or benzodiazepines consider *stopping their drug use altogether*. If you think you might want to do this then you should speak with your doctor or specialist drug worker. *Do not suddenly stop* taking opiates (methadone, DF118, heroin) or benzodiazepines (e.g. valium) as this could be risky for you and your

baby. If you want to come off, it is best done under medical supervision, so that your baby can be monitored carefully and you can be given support.

Alcohol……heavy drinking during pregnancy (including 'binge' drinking) is associated with a number of pregnancy complications and birth defects. If you are drinking more than 2 small drinks every day and can't stop or reduce your drinking, then talk to your doctor or midwife who can arrange specialist help. If you are drinking heavily (more than 6 drinks a day) then you should get help straight away. Because we don't really know what is a 'safe' amount to drink in pregnancy we recommend no more than one small drink per day, preferably none.

Drugs and the newborn baby

If you are taking drugs (e.g. opiates and benzodiazepines) most days throughout your pregnancy and right up until the time of birth, your baby will have been exposed to these drugs and may develop *withdrawal symptoms* after birth. It is difficult to predict how each baby will react. It depends on what drugs you have been taking, how much and for how long. It also depends on the baby's ability to clear the drugs from their system.

If your baby does develop withdrawal symptoms, these are usually *easily managed* and the *baby will recover in time*. Sometimes, however, withdrawals can be quite severe and the baby will need special medical and nursing care in hospital (in the 'neonatal unit' or 'special care baby unit'), perhaps for several weeks.

Your baby will be monitored closely for signs of withdrawal for at least the first 3 days and you will be given advice on how to comfort and care for your baby if withdrawal symptoms do develop.

Most babies are well enough to go home after 3 days but may need some special attention from you, the Midwife, Health Visitor and GP for some time afterwards (who will want to check on how well the baby is feeding, sleeping and gaining weight).

Antenatal care (before the birth)

When you are pregnant it is very important that you are checked regularly and attend for all your scans and other tests. Women (and their babies) who get regular antenatal checks tend to do better than those who don't. Midwives are there to help you and will try to answer any questions and fears that you may have. When you see the midwife, let them know about your drug and alcohol use so that you can be offered the special care you and your baby need.

If you have a *drug worker*, tell them you are pregnant so that they can help you with aspects of your drug use during pregnancy. You might also need a *social worker or welfare rights worker* to help with benefits or any other social problem (e.g. housing, debts, legal problems etc).

Normally, the midwife will organise a *meeting* around the 28th week (seven months) of your pregnancy to discuss how things are going and to plan ahead for the arrival of your baby. You (and your partner if you wish) would be asked to meet with professionals involved in your care so that any support that you might need can be arranged well in advance.

HIV, hepatitis B and hepatitis C

Your midwife will offer *routine* testing for HIV and hepatitis B at your antenatal '*booking*' appointment. These viral infections can pass from mother to baby. Treatment can now greatly reduce the likelihood of your baby getting these infections so it is important you get tested. If you have *injected* drugs or had *unprotected sex* with anyone who has, you could be at risk of HIV, hepatitis B and hepatitis C. Your midwife or GP will normally offer testing for hepatitis C if you have been at risk. If you are injecting drugs we recommend getting immunised (vaccinated) for hepatitis B as well.

Labour and childbirth

Most women who use drugs or alcohol have a *normal* labour and a *normal* delivery. The obstetrician and paediatrician will get involved if there are any complications. Some women worry about whether or not they will be given enough pain relief… you don't need to. You will get to take your prescribed drugs *as normal* in hospital *and* you will also be given additional pain relief when you need it. It is important that hospital staff know what drugs you are taking (including any street drugs), as this will affect what pain relief is given (for instance there are some drugs that don't work with methadone, heroin and DF118).

You need to let hospital staff know the name and telephone number of your *pharmacist* (chemist) and prescribing *doctor*. It is *hospital policy* to cancel prescriptions before dispensing drugs in the maternity wards. You should take all your medication into hospital with you and show it to the staff. Be reassured that whilst you stay in hospital your *privacy* will be maintained at all times.

Breastfeeding

You will be given *lots of encouragement and help* to breastfeed, provided your drug use is fairly stable. The *exception* to this would be if you were HIV positive or using large amounts of stimulants (e.g. cocaine/'crack') or street benzodiazepines (e.g. valium) or drinking heavily. Only small amounts of drugs are passed to the baby through breast milk and there is no evidence that hepatitis C is passed to the baby through breastfeeding either. Breastfeeding has *lots of benefits* for the long-term health and development of your baby. If you do successfully breastfeed and continue to take drugs then you will be advised to *slowly wean* the baby onto solids when the time is right. Your Health Visitor will give you advice about this.

Postnatal care (after the birth)

After your baby is born you will be asked to stay in hospital for at least *3 days* (72 hours) so that your baby can be checked for withdrawal symptoms. Following childbirth you might notice that your *normal dose* of drug affects you *more than normal*. This is something to be careful of as over-sedation ('gouching') may mean that you could accidentally drop your baby or not hear them crying.

After you *leave* hospital with your baby, the *midwife* will visit you at home. When your baby is 11 days old, your *health visitor* will visit and will be a good source of information and support on *motherhood* and all aspects of health for you and your baby. There will be *baby clinics* at your local doctor's surgery or health clinic where the development of your child will be assessed. Some areas also have local *parent and child groups* and *breastfeeding support groups* to go to as well.

It is important that you are clear about what is expected of you as a mother and what services are available to help.

The time after the baby is born can be difficult for some mothers. Tiredness and lack of sleep, as well as the 'baby blues' and other stresses (like the baby still having some withdrawal symptoms) can make it harder to look after your baby. This is *normal* and your midwife, health visitor, doctor and drug worker are there to talk to and offer support.

Midwifery care staff

Midwives are specially trained in pregnancy and childbirth. Obstetricians are doctors who care for women in pregnancy and childbirth. Neonatologists are doctors who care for newborn babies. Paediatricians are doctors who care for children. Health Visitors are specially trained in child and family health. All these health professionals, along with your GP of course, may be involved in the care of you and your baby.

Other services

Specialist drug and/or alcohol services may be able to offer you a lot of help whilst you are pregnant and after your baby is born. Ask your doctor or midwife for advice about how to contact them. Specialist services give priority to pregnant woman and will see you very quickly.

Some women worry that their baby may be 'taken into care' just because they use drugs. Drug use *in itself* is not a reason to involve the Social Work Department or to *assume* you cannot care for your baby. If there is concern about the *safety or welfare* of your child however, Social Work may need to do an assessment and get involved. This is the same policy for *everyone*, whether or not they use drugs.

In Lothian, we have a good system of health and social care that works well with people who use drugs or alcohol. Everyone is interested in the well-being of you and your baby and want to make your experience of pregnancy and childbirth a happy one. Please feel free to talk to professionals. They are there to help.

Getting support

It is very important that as many people as possible can offer you support throughout your pregnancy and beyond. Show this booklet to your partner and any other person (family or friends) who will be supporting you. There are a lot of myths about drug use in pregnancy and a lot of bad feelings towards mothers who use drugs so it is important you get reliable information and have a positive experience.

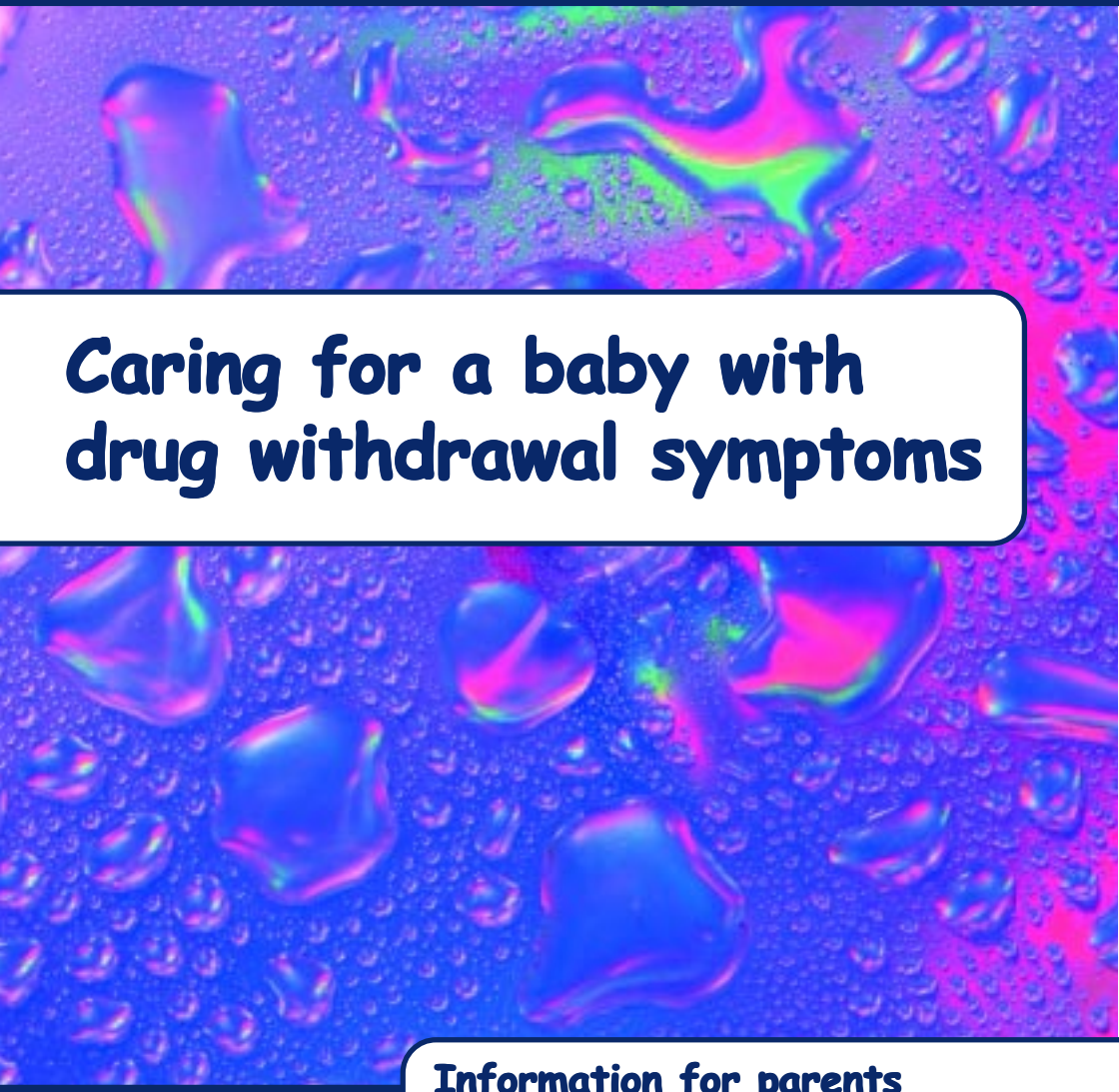
If your partner also has problems related to drugs or alcohol then they can get help from services at the same time as you, if they are not already doing so. Tell them to speak to the midwife or their GP.

Helpful numbers

	Telephone number
My Midwife is	
My Obstetrician is	
My Maternity Hospital is	
My Pharmacist is	
My Health Visitor is	
My Drug / Alcohol Worker is	
My Social Worker is	
Other workers involved in my care	

Notes

NHS Lothian



Caring for a baby with drug withdrawal symptoms

Information for parents

This leaflet provides you with information and advice that will help you prepare for the arrival of your baby. Hopefully after reading this, you will feel reassured and confident that your baby can be well cared for and that you can do a lot to help.

If there is anything in this leaflet that you don't understand or would like to talk about further, please speak with your midwife or other health care professional involved in your care.

Drug use and newborn babies

Most drugs (including tobacco and alcohol) that you take when you are pregnant pass through the placenta and are absorbed by your baby.

If a mother is *dependent* (or 'addicted') to certain drugs the *baby* will be born dependent on these too and can develop what is known as '*Neonatal Abstinence Syndrome*'. This is a condition where the baby shows signs and symptoms of withdrawal. It occurs often with opiate drugs (e.g. methadone, DF118 or heroin) and benzodiazepine drugs (e.g. valium or temazepam). At birth, the baby's drug supply stops and the baby goes through a period of withdrawal. Baby withdrawal symptoms can be similar to how adults feel when they suddenly stop taking drugs or go 'cold turkey'.

Baby withdrawal symptoms can include things like:

- high-pitched crying
- irritability and restlessness
- tremor (shakiness)
- feeding difficulties (the baby is often keen to feed but cannot suck or swallow properly)
- sleeping difficulties (the baby cannot settle or sleep after a feed)
- vomiting and/or diarrhoea
- fever
- a sore bottom (due to frequent dirty nappies)

Occasionally, babies have convulsions (fits) but this is very rare.

Most babies who have been exposed to drugs before birth will have some symptoms after birth. Some babies experience only mild withdrawal symptoms and require no more than the usual care that all babies need. Other babies however, can have severe symptoms where they cannot feed or sleep properly and they lose weight rather than gain weight. These babies usually need medical treatment, including special nursing care and sometimes calming drugs to help them recover.

Unfortunately, there is no way of telling exactly how a baby will react as there are many different factors that affect withdrawal symptoms in babies. The *amount* of drugs you are taking is only one factor so we like to prepare all parents just in case.

What we can say is that drug withdrawal in babies is now fairly common, so you are not alone. Midwives and other maternity staff as well as Health Visitors and GPs have experience in looking after babies and can offer some good advice and help to parents.

Caring for your baby

Mothers who are dependent on drugs are asked to stay in hospital with their baby for at least 3 days (72 hours). This is because most withdrawal symptoms in babies appear within this time period. Benzodiazepines (e.g. valium and temazepam) however, can take longer to leave the baby's system and withdrawal signs may not show up for a week or so.

In the *postnatal ward* you will be encouraged to *breastfeed* and '*bond*' with your baby. The nurse or midwife will use a special score chart to assess the condition of your baby. You will be shown how to use the chart so you can help the nurses with this.

Most babies are well enough to go home after 3 days where they can be cared for by their parents, with the help and support of the midwife, health visitor and GP. The baby needs to feed well enough and the baby will be checked to see if it is putting on enough weight.

Parents are encouraged to keep a close eye on their baby and use the special score chart.

If the baby has severe withdrawal symptoms they would be admitted to the 'neonatal unit' or 'special care baby unit'. Here they can get 'tube' feeds and calming medicine if necessary. Treatment aims to reduce the baby's distress and to get the baby feeding and sleeping as normally as possible. Babies usually stay in the neonatal unit for about 10-14 days, but occasionally for much longer.

Most admissions to the neonatal unit happen when the baby is still in hospital after birth, but babies are also admitted from home if problems become worse later on. Babies older than 2 weeks are admitted to the Royal Hospital for Sick Children (RHSC) or the Children's Ward at St John's Hospital. If the baby's problems get worse at home then it is better to admit the baby earlier rather than later. This is why we are keen to offer parents extra help at home and to see how the baby is doing.

We appreciate that babies with withdrawal symptoms are difficult to look after and they can require a lot of patience and may be difficult to feed and settle. Some babies can be irritable for months, but symptoms gradually improve with time.

Things parents can do to help

You will have been given this leaflet because your baby may be at risk of developing withdrawal symptoms. Experience has shown us that there are many things that you can do to help calm and comfort your baby.

Here are some suggestions:

- make sure your baby is kept in very quiet and calm surroundings, no bright lights or loud sounds that might upset your baby
- make sure no one smokes near your baby, keep the air fresh but warm
- hold your baby as much as you can, the baby will cry less and feed better if they have 'skin-to-skin' contact
- use a dummy or pacifier ('soothers')... unless you are breastfeeding
- move and handle your baby very gently; try giving them a gentle massage
- change your baby's clothes frequently, especially if they sweat a lot
- avoid getting your baby too hot
- regularly check and change your baby's nappy
- use a barrier cream around the baby's bottom area to help prevent any skin damage
- feed your baby on demand, frequent small feeds are normally better
- keep a record of all the feeds your baby takes so that the Midwife or Health Visitor can check whether your baby is feeding well enough and putting on enough weight
- if your baby has a convulsion (fit), dial 999 and ask for an ambulance to take your child to the Royal Hospital for Sick Children.

Breastfeeding and drug use

All mothers are encouraged to breastfeed their babies and are given help to do so, including mothers who are dependent on drugs. In fact, breastfeeding can sometimes help with your baby's withdrawal symptoms. Only very small amounts of drugs are passed to the baby through breast milk. The benefits of breastfeeding are so great that they outweigh worries about continued drug use. The only exceptions to this would be: if the mother were HIV positive (or 'at risk' of infection whilst breastfeeding); if she were drinking heavily, taking large amounts of stimulant drugs (e.g. cocaine, crack or 'speed') or street benzodiazepines (e.g. valium).

It is important to remember that most women who use drugs have a normal pregnancy, a normal delivery and a normal full term baby. Babies born with drug withdrawal symptoms will recover in time.

We hope that this leaflet has given you enough information to help you prepare for the arrival of your baby. We know that it can be difficult to have a baby with withdrawal symptoms and that many mums feel guilty and 'to blame'. Remember that we are always here to provide you with support and to talk to you about any worries or questions that you may have. Please feel free to speak with your midwife or other health care professional about the information in this leaflet.