4. ANTENATAL AND POSTNATAL MENTAL HEALTH: POPULATION, DISORDERS AND SERVICES

4.1 SCOPE OF THE GUIDELINE

This guideline covers the mental healthcare of women with mental disorders who are pregnant or in their first postnatal year. The latter period was determined after a review of the literature and research in this field but aspects of the guidance may be considered appropriate to the mental healthcare of mothers of children over 1 year old. The guideline is concerned with the broad range of mental disorders seen in adults, including both common mental disorders, such as anxiety, and severe and enduring disorders, such as schizophrenia. However, it focuses on the aspects of their expression, risks and management that are of special relevance in the antenatal and postnatal periods. Thus, the guidelines should be used in conjunction with other NICE guidance specific to disorders or interventions (see www.nice.org.uk).

The guideline also makes recommendations about the services required to support the delivery of effective detection and treatment of most mental disorders in the antenatal and postnatal periods in primary and secondary care. It will also be relevant to (but not make specific recommendations for) non-NHS services such as social services and the independent sector.

The optimisation of psychological well-being, as opposed to the management of mental disorders, is not covered in this guideline. However, the importance of this to the healthcare of women antenatally and postnatally is implicit and the guideline should be applied in conjunction with those NICE guidelines relating to antenatal and postnatal healthcare.

The mental health needs of fathers, partners, other carers and children, whose health and functioning will inevitably be affected by mental disorders in women, are also important and should not be neglected, and their needs have been considered in developing the recommendations in this guideline. In relevant places, the phrase 'fathers/partners and carers' has been used to remind readers of the continued importance of thinking about mental illness within the context of the family. There are currently NICE guidelines covering the treatment of several mental health problems, including depression and a number of anxiety disorders, which should be followed when considering the treatment needs of families. The GDG considered carefully the population covered by the guideline and common terminologies such as 'users', 'sufferers', 'survivors' and 'patients'. For convenience, the guideline refers to the target population being considered throughout as 'women', with a specifier as necessary, such as 'women with pre-existing schizophrenic illness'.

As can be seen from the above, it is mainly the context of care, namely during pregnancy and the postnatal period, that is the primary focus of the guideline, rather than significant differences in the nature of the particular disorders. In particular, the biological, physiological, psychological and social changes that occur at this time influence the nature of both detection and treatment of mental disorders. Much of the guideline is concerned with the balancing of the risks and benefits of treatment and not treating illness at a particularly critical time in the lives of women, the fetus, siblings and families.

Case vignettes are used throughout the text to illustrate women's experiences of mental illness, health and services in the antenatal and postnatal periods; the intention behind the use of these vignettes is to add to the understanding of individual experience described in this guideline.

4.2 MENTAL DISORDERS DURING PREGNANCY AND THE POSTNATAL PERIOD

4.2.1 Introduction

Women in the antenatal and postnatal period are vulnerable to having or developing the same range of mental disorders as other adults, and the nature and the course of the large majority of these disorders is common to all adults (Brockington, 1996). However, the nature and treatment of mental disorders occurring in the antenatal and postnatal period differ in a number of important respects:

- There is a risk of pregnant women with an existing disorder stopping medication, often abruptly and without the benefit of an informed discussion, which can precipitate or worsen an episode.
- In women with an existing disorder (for example, bipolar disorder), there may be an increased risk of developing an episode.
- The impact of any disorder may often require more urgent intervention than would usually be the case because of its effect on the fetus and on the woman's physical health and care, and her ability to function and care for her family.
- Postnatal-onset psychotic disorders may have a more rapid onset with more severe symptoms than psychoses occurring at other times (Wisner & Wheeler, 1994) and demand an urgent response.
- The effects of disorders at this time demand that not only the needs of the woman but also those of the fetus/infant, siblings and other family members are considered (including the physical needs of the woman or fetus/infant) – for example, when considering admission to an inpatient bed.
- The shifting risk/benefit ratio in the use of psychotropic drugs in pregnancy and breastfeeding requires review of the thresholds for treatment for both pharmacological and psychological treatments. This may result in a greater prioritisation of prompt and effective psychological interventions.

4.2.2 Course and prognosis of mental disorders in the perinatal period

There is little evidence that the underlying course of most pre-existing mental disorders is significantly altered during this time, with the exception of bipolar disorder, which shows an increased rate of relapse and first presentation (see Section 4.3.4). Similarly, there is little evidence that the prognosis of disorders that develop during pregnancy or postnatally are significantly different from those developing at other times (Brockington, 1996). However, there is evidence of possible adverse outcomes for infants and siblings of many disorders at this time. Maternal mental illness at this time may negatively affect the woman's relationship with her partner and increase the partner's risk of mental illness (Lovestone & Kumar, 1993). As with other mental disorders, the concept of prognosis must therefore be extended to consideration of not only the future course of the disorder and its impact on the woman, but also its impact on the other family members. Healthcare professionals should also consider that many women may have considerable anxiety about disclosing a mental disorder and may fear that their baby may be taken away. The focus of both the mother and of services on the needs of the infant should not obscure the needs of the mother.

4.2.3 Pregnancy and birth in England and Wales

In 2004 there were 639,721 live births. The average age of women giving birth was 29, with the average age of primiparous women being 27 and with 7% of births being to women under the age of 20 years. Of women giving birth in England, 85% were married or cohabiting and 15% were lone parents. Sixteen percent of children were born into low-income households. In 2000 there were 0.13 maternal deaths per 1,000 live births (this compares with figures of 0.24 per 1,000 for the whole of Europe and 0.17 per 1,000 for the USA). In England and Wales in 2002, there were 2,101 neonatal deaths (3.52 per 1,000 live births); this compares with figures of 4.7 per 1,000 live births in the USA in 2002 and 2.8 per 1,000 in Australia in 2004.

Social factors can play an important role in both the aetiology and maintenance of mental disorders. The above figures, showing significant numbers of women bringing children up alone, in poverty or in suboptimal accommodation, serve to emphasise the vulnerability of some women and their children. Such adversity may play an important role in maintenance of mental disorder in adults (Brown & Harris, 1978). In addition, the increased psychological vulnerability of children whose parents have a mental disorder (Beardslee *et al.*, 1983; Rubovits, 1996) argues strongly for the effective and prompt treatment of mental disorder in pregnancy and the postnatal period.

4.2.4 Special considerations for adolescents

The UK has a high rate of pregnancy amongst adolescents, and this raises the issue of consent for this group. For example, when admitting an adolescent to inpatient care, it is desirable to do so with the informed consent of both the adolescent and her parents,

not least because the success of any treatment approach significantly depends on the development of a positive therapeutic alliance involving the adolescent, the family and the inpatient team. However, there will be times when the professionals consider admission to be necessary but either the adolescent or her family do not consent.

If an adolescent younger than 18 years refuses treatment, but the parent (or guardian) believes strongly that treatment is desirable, then the adolescent's wishes may be over-ruled. However, an adolescent has the right to consent to treatment without involving the consent of parents after his or her 16th birthday. A child under the age of 16 has a right to consent to treatment if he or she is assessed as being mentally competent (known as 'Gillick competence' after Victoria Gillick who brought a case against a health authority after a health department circular advised that doctors could prescribe contraception to under sixteens without parental consent [see Gillick, 1985]. Since the subsequent decision on the case by the House of Lords went against Mrs Gillick, this is also known as 'Fraser' competence after the judge presiding over the original case). Healthcare professionals need to be mindful of whether a child or adolescent is subject to an order under the Children Act (1989). In most cases, the use of the Mental Health Act (1983) should be considered as it includes safeguards such as involvement of other professionals, a time limit and a straightforward procedure for appeals and regular reviews.

Those professionals involved in assessing children or adolescents for possible inpatient admission (tier 4 child and adolescent mental health services [CAMHS] staff) should be specifically trained in issues of consent and capacity, the use of current mental health legislation and the use of childcare legislation as it applies to this group of patients. They should seek specialist perinatal advice if necessary.

4.2.5 Critical practice recommendation

4.2.5.1 Healthcare professionals working with adolescents experiencing a mental disorder during pregnancy or the postnatal period should:
- be familiar with local and national guidelines on confidentiality and the rights of the child
- obtain appropriate consent, bearing in mind the adolescent's understanding (including Gillick competence), parental consent and responsibilities, child protection issues, and the use of the Mental Health Act and of the Children Act (1989).

4.3 INCIDENCE AND PREVALENCE OF PERINATAL DISORDERS

The purpose of this section is not to provide an exhaustive overview of the epidemiology of perinatal disorders but to highlight important issues about the incidence and prevalence of perinatal disorders, particularly if they are different from that found in general adult disorders. The commentary below is also limited as a result of the paucity of research in this area. Most studies to date have focused principally on depression and psychotic illness, mainly in the postnatal period, and studies of

depression have generally relied on the use of self-report measures applied at isolated time points. Therefore, caution must be applied to the interpretation of the data. In particular, caution is needed in the use of the term 'postnatal depression' as there is concern that its misuse is widespread, with potentially serious negative consequences. These include its use in clinical situations as a label for any mental illness occurring postnatally and has been pointed to in the Confidential Enquiry into Maternal and Child Health as a major concern because other serious illnesses fail to be identified as a consequence (Lewis & Drife, 2004). It also reinforces the view that postnatal depression is somehow different from depression at other times. Common false beliefs include the idea that its symptoms and effects are less severe, that it goes away by itself, that it is somehow associated with whether or not the woman is breastfeeding, that it is all due to hormones, that it has no risk of non-puerperal recurrence, that it carries an inevitable risk of future postnatal recurrence, that depression is less common antenatally or that depression that is already present before birth is not the same thing. All of these assumptions are misleading and can lead to disadvantageous and inappropriate responses by clinicians and women themselves. In addition, they can lead to policy and service development focused on depression postnatally, to the exclusion of the full range of mental disorders occurring antenatally and postnatally, all of which can potentially have serious effects on woman, infant and the family.

It is therefore recommended that, for the purpose of diagnosis, usual diagnostic guidelines for each condition, such as those contained in *The ICD-10 Classification of Mental and Behavioural Disorders* (ICD-10) (World Health Organization [WHO], 1992) and the *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association (DSM-IV) (APA, 2000) be followed. Clinicians should bear in mind that some changes in mental state and functioning are a normal part of the antenatal and postnatal experience and should, therefore, be cautious about basing any diagnosis largely on such features without careful consideration of the context. Such features include, for example, sleep disturbance, tiredness, loss of libido and anxious thoughts about the infant.

4.3.1   Anxiety disorders

Anxiety disorders are often comorbid with depressive disorders (NCCMH, 2004) and this link seems also to be true for pregnant women (Heron *et al.*, 2004). This has implications for the identification and management of anxiety disorders in pregnancy.

Panic disorder
Little systematic research has been undertaken on panic disorder in pregnancy and the postnatal period. A review of studies examining the occurrence of panic disorder (without concurrent affective disorder) during pregnancy and/or the postnatal period found ten studies, all except one of which were retrospective and uncontrolled (Hertzberg & Wahlbeck, 1999). One study was concerned with onset of panic disorder in the postnatal period (Sholomskas *et al.*, 1993), and the rest documented the course of existing panic disorder. Overall, the review found that symptoms improved in 41% of pregnancies

(89 of 215), and 38% had postnatal onset (105 of 278), although in most studies (n = 8), the postnatal period was defined as up to 3 months after delivery. There is no suggestion of a raised prevalence of panic disorder in pregnancy.

Generalised anxiety disorder (GAD) and symptoms of anxiety
While in a small American study (n = 68) 4.4% met criteria for GAD (based on the Structured Clinical Interview for DSM-IV [SCID-IV]), with nearly 28% having subsyndromal symptoms (Wenzel *et al.*, 2003), the prevalence of anxiety symptoms is much higher. For example, a large-scale community prospective study of around 8,300 women (based on the Avon Longitudinal Study of Parents and Children (ALSPAC)), which measured anxiety symptoms during pregnancy and the postnatal period (from 18 weeks' gestation to 8 months postnatally), found while 14.6% scored above threshold at 18 weeks' gestation (a score of 9 or more on the anxiety items of the Crown-Crisp Experiential Index (CCEI) [Crisp *et al.*, 1978]), 8% scored above threshold at 8 weeks postnatally, with 2.4% *de novo* presentations (Heron *et al.*, 2004). Two-thirds of women reporting anxiety during pregnancy reported anxiety postnatally. The study was based on a self-report questionnaire. Despite the view that anxiety disorders only constitute mild mental health problems, they contribute to significant disability to sufferers and this combined with the emerging evidence of possible negative effects on the fetus, demonstrable in infancy, reinforces the view that more attention needs to be paid to these disorders.

Obsessive-compulsive disorder (OCD)
A review of symptoms of OCD in pregnancy and the postnatal period found some evidence for onset of OCD associated with pregnancy and childbirth, although studies were of OCD populations and relied on retrospective self-report (Abramowitz *et al.*, 2003). The authors could find no studies examining prevalence of pregnancy-related OCD in the general population. The review also found no difference in levels of OCD symptomatology in women with depression in the postnatal period compared with women with depression at other times, although a large proportion of both groups had symptoms. In common with the general population, OCD symptoms were much more common amongst women who were depressed postnatally than amongst those who were not (41% versus 6%). The studies did not report on the potential impact of OCD on the mother-infant relationship.

Post-traumatic stress disorder (PTSD)
Symptoms of PTSD following childbirth have been reported in a number of women. A review of links between childbirth and PTSD in women following a live birth found prevalence figures for a 'PTSD-profile' (that is, symptom criteria of DSM-IV B, C and D) of between 2.8% and 5.6% at around 6 weeks postnatally, which reduced to 1.5% by 6 months postnatally (Olde *et al.*, 2006). This is consistent with the usual course of PTSD, which appears to have a high remittance rate following the index traumatic event (NCCMH, 2005). The rate in studies using DSM-IV criteria was between 1.7% (1 to 13 months postnatally) and 2.8% (6 months postnatally). Czarnocka and Slade (2000), in a self-report questionnaire study, found that 3% of their sample of 264

women showed clinically significant levels on all three PTSD dimensions and 24% on at least one dimension. The estimates for PTSD in non-childbearing community samples report 12-month prevalence rates between 1.3% (Creamer *et al.*, 2001) and 3.6% (Narrow *et al.*, 2002). Estimates for the 1-month prevalence rate range between 1.5% and 1.8% using DSM-IV criteria (Stein *et al.*, 1997; Andrews *et al.*, 1999), and 3.4% using the less strict ICD-10 criteria (Andrews *et al.*, 1999), suggesting that rates for postnatal women are broadly in the range for the rest of the general population. PTSD experienced by some women at this time may not be induced by traumatic delivery but will be pre-existing PTSD connected with traumatic events unrelated to the current context, though it may still have a significant impact on the woman, infant and family. Stillbirth has also been identified as a stressor for PTSD symptoms during the subsequent pregnancy (Turton *et al.*, 2001).

4.3.2 Eating disorders

Anorexia nervosa in pregnant women is less common than in the general population, due to the reduced fertility and fecundity associated with this disorder and its usual onset in adolescence. In a follow-up study of people with anorexia nervosa (n = 140), fertility was reduced to one third of the expected rate (Brinch *et al.*, 1988). However, pregnancy in women with bulimia nervosa is less rare since this disorder is less likely to cause infertility, although as many as 50% may suffer from amenorrhoea or oligo-amenorrhoea (Fahy & Morrison, 1993) at some point in the course of the illness. However, oligoamenorrhoea or vomiting oral contraceptives may increase the risk of unplanned pregnancy amongst women with bulimia nervosa (Morgan *et al.*, 1999). Turton and colleagues (1999) found an apparent improvement in eating disorder symptoms during pregnancy, with 4.9% of women (n = 410) scoring below threshold on the Eating Attitudes Test (Garner & Garfinkel, 1979) during pregnancy, but 10% scoring above threshold for the 2 years before conception. There was an overlap of about 33% between the two groups. Three per cent (of 370 complete datasets) reported symptoms during pregnancy, 6.8% scored below threshold during pregnancy but above in the 2 years before and 1.4% did not score above threshold during the 2 previous years, but scored above threshold during pregnancy. However, it should be noted that the 2-year data were collected retrospectively so are likely to be subject to bias. Factors associated with higher scores in pregnancy included younger age (less than 29 years), previous symptomatology, lower educational attainment, poorer housing, employment status and previous miscarriage. Women with eating disorders during pregnancy are also more likely to have obstetric problems, such as miscarriage, delivery by caesarean section and premature or small infants (Brinch *et al.*, 1988; Bulik *et al.*, 1999).

4.3.3 Depression

Depression is a common disorder and is associated with major disability when following a chronic course (WHO, 1992), but it is not the only mental disorder of the

antenatal or postnatal period, despite its dominance in the perinatal mental health literature. The estimated point prevalence for major depression among 16 to 65 year olds in the UK is 21/1,000 (males 17, females 25), but, if the less specific and broader category of 'mixed depression and anxiety' (F41.2, ICD-10, WHO, 1992) is included, these figures rise dramatically to 98/1,000 (males 71, females 124). In mixed depression and anxiety, it can be seen that the gender ratio is more skewed to females (Meltzer *et al.*, 1995a & 1995b). Differential rates of prevalence of depression are identified in the same study, being highest among the separated (56/1,000 female, 111/1,000 male), next highest among widowed males (70/1,000) and divorced females (46/1,000), with the lowest prevalence among the married (17/1,000 and 14/1,000 respectively). Lone parents have higher rates than couples, and couples with children higher rates than those without children (Meltzer *et al.*, 1995a & 1995b). However, these studies do not report prevalence rates among pregnant women or women in the postnatal period. Epidemiological studies have also established that, for most, depression is a chronic disorder. In a WHO study, 66% of those identified as suffering from depression were still found to satisfy criteria for a mental disorder a year later, and for 50% the diagnosis was depression. It is probable that widely differing rates between the clinics studied in the countries in which the data were collected reflect true differences in prevalence in these clinics rather than differing concepts of depression between countries (Simon *et al.*, 2002).

Although research and clinical care has generally placed the greatest emphasis on the postnatal period, depression during pregnancy is still of considerable importance. A high-quality review of depression in the perinatal period, which used meta-analysis to combine point prevalence estimates from large-scale studies, estimated the point prevalence of major depression (that is, the rate at a particular point in time) as 3.8% at the end of the first trimester, 4.9% at the end of the second and 3.1% at the end of the third trimester (Gavin *et al.*, 2005). The same review estimated the postnatal point prevalence at between 1% and 5.7% in the first 12 months postnatally, with the highest rates at 2 months (5.7%) and 6 months (5.6%). Gavin and colleagues calculated the period prevalence (that is, the rate over a period of time) as 12.7% during pregnancy, 5.7% from birth to 2 months postnatally, 6.5% at 6 months and 21.9% at 12 months. However, for most of these estimates, only a single study was found. The estimates contrast with a large-scale community prospective study of around 8,300 women (based on the ALSPAC), which measured depressive symptoms during pregnancy and the postnatal period (from 18 weeks' gestation to 8 months postnatally) and found that depression scores were higher at 32 weeks' gestation than at 8 weeks postnatally, with 13.5% scoring above threshold for probable depression at 32 weeks and 9.1% at 8 weeks postnatally (Evans *et al.*, 2001). The study used self-report measures (Edinburgh Postnatal Depression Scale [EPDS] and CCEI) and did not confirm diagnoses of depression.

The variation in rates found is probably a result of different populations studied. It should be noted that Gavin and colleagues (2005) used only studies where depression had been diagnosed according to recognised criteria rather than self-report measures. These authors concluded that it was not possible, given the currently available research, to state with any certainty whether there is a difference in rates between pregnancy trimesters or between months postnatally.

Postnatal women do report higher levels of depressive symptoms and interpersonal problems, particularly marital adjustment (O'Hara *et al.*, 1990). Although this prevalence rate is no greater than that expected in the general female population, one study, which provides data on postnatal incidence (number of new cases with postnatal onset), indicates that this may be raised approximately threefold in the first 5 weeks postnatally, although it has been suggested that this higher rate may be largely the result of the higher rates in mothers of young children; this difference disappears by 6 months postnatally (Cox *et al.*, 1993). Gavin and colleages (2005), although noting this study, concluded that there was no evidence that prevalence was higher for women in the perinatal period compared with other times. There is also no increased risk for depression in the postnatal period following an emergency caesarean (Patel *et al.*, 2005).

The Confidential Enquiry into Maternal Deaths (Lewis & Drife, 2004) has found that, for the last 9 years, psychiatric disorders have been the leading cause of maternal death in the UK, with over half of these deaths being due to suicide. For the period 1997 to 1999, depression is the mental disorder associated with the greatest number of suicides, although the rates for lifetime risk of suicide are significantly lower than those for some other less common disorders such as bipolar disorder (Lewis & Drife, 2004; NCCMH, 2006). The majority of suicides in pregnant and postnatal women (about 60%) occur in the 6 weeks before delivery and the 12 weeks after delivery. Although suicide is the most common cause of death in the perinatal period and women with severe mental illnesses have high rates of suicide postnatally, the rates of suicide for women in the antenatal and postnatal periods are lower than that for the whole female population (Appleby, 1992; Appleby *et al.*, 1998;), although there is some suggestion that rates are higher in younger women who have recently experienced a termination (Gissler *et al.*, 2005).

Vignette: A woman with pre-existing depression and depression after birth of both of her children

Before I first became pregnant in February 1998 at the age of 33, I had been taking an antidepressant for around 3 years for what a consultant psychiatrist termed 'classic diurnal depression', which included debilitating symptoms of claustrophobia and agoraphobia. Although in a long-term relationship since 1987, I had previously dismissed the notion of having children – being able to look after them and build a loving relationship – because of my depression. I had been back and forth to my GP with depression for years. I'd never discussed with anyone my anxieties about having children, but I believe some form of cognitive behavioural therapy (CBT) with the right person would have been hugely helpful if it had been suggested or on offer years earlier.

The pregnancy was an extremely happy time. Although I came off the antidepressant as soon as I discovered I was pregnant (this was my own

Vignette: (*Continued*)

decision), apart from some short-term, unpleasant physical symptoms (dizziness and so on) my mood was positive and I coped well with work and the new demands on my body. Already aware that there was a good chance of becoming depressed once my baby was born, I emphasised my worries on this score right at the beginning of my antenatal care at the GP practice. But, although I raised it time and again, and it was written clearly in my notes, it was never referred to by any healthcare professional.

Two weeks after my due date, in November 1998, I went into labour following two doses of prostaglandin gel/pessaries. After a day and a half, during which time there were oxytocin drips, cranial scrapes, constant monitoring, and so on, the doctors decided on an emergency caesarean section as there was some concern about the baby's safety. By the time my daughter was born, I was extremely distressed and unable to feel any joy or sense of 'achievement'. But she latched onto my breast as soon as we were back in the ward, and we were able to begin to bond, although my feelings for her were very confused. There was no discussion of the likelihood of postnatal depression before my discharge from hospital or during the postnatal care from the midwives.

Fourteen days after my daughter's birth I began experiencing familiar, but much more dramatic, feelings of despair, panic and inability to cope. I tried to just 'get through it' as I believed I could not ask for treatment with antidepressants, but it was nightmarish both for me and my partner; we had no family support, apart from my sister, who has a family of her own, and lives 200 miles away.

At my 6-week check, the SHO at the hospital was extremely unsympathetic about my very strong desire to continue breastfeeding. Both she, and a female GP, told me it was breastfeeding OR antidepressants. I think I remember that I did begin taking antidepressants then, but after doing some very basic searches on the internet, made the unilateral decision to continue to breastfeed: I felt my recovery and my relationship with my child depended on it. The depression began to lift after another 6 weeks or so, but not before my partner had almost resigned his job to look after us and I had thoughts of suicide and putting my daughter up for adoption. I was terrified of being on my own with the baby: rationally I knew I could cope and that nothing would happen to her, but I would beg my partner not to leave and thought no one else would want to spend time with me. I made one visit to the hospital's psychiatric emergency clinic but was strongly advised not to seek admission. I think I started feeling optimistic, and that I could cope on my own for hours at a time, in around April or May 1999. I continued taking the antidepressant for around 2 years.

For the next 3 years, we struggled with parenthood but developed a strong relationship with and love for our daughter. I wanted her to have a sibling,

Vignette: (*Continued*)

but felt I wouldn't be able to cope and that I might not recover from another bout of postnatal depression. But after going back on antidepressants in 2002, we decided to try for a second baby and, in February 2003, I conceived. The pregnancy progressed much as the first; I stopped taking antidepressants at once and felt happy and well for most of the time, although I was much more tired, working 4 days a week and having a lively 4 year old. At almost every antenatal appointment I talked about my worries about postnatal depression, but it was only at my 38-week check that the consultant took these on board and made an 'emergency' appointment with a consultant psychiatrist. When we met, I was 39 weeks pregnant and, after discussing my medical history, she suggested that I had around a 65% chance of becoming postnatally depressed again. So I agreed that I would begin to take a 50 mg daily dose of an antidepressant 2 days after the baby's birth and arrange to see my psychiatrist regularly. There was a lot of stress about getting the antidepressant medication from the pharmacy at the hospital where I gave birth, with several comments along the lines of 'Well, you'll have to stop breastfeeding now'. If I hadn't been able to argue for them, I would not have got them.

My second child, a son, was also born by emergency caesarean section, following placental abruption when I was around 5 cm dilated. I was disappointed not to have a 'normal' delivery but, unlike the first time, accepted quickly that a safe delivery and a healthy baby were the main priorities. Like his sister, my son breastfed well immediately and, when I went home, I felt quite rested and optimistic. However, my daughter immediately stopped wanting to sleep on her own in her room, so night-times became exhausting very quickly. After about 2 weeks, I started feeling extremely anxious, became unable to sleep and was worried that if I became seriously depressed again I might not recover; perhaps this time the drugs wouldn't help.

At around 3 weeks, after having the dose of my antidepressants increased to 100 mg, I had developed severe panic attacks in which I experienced tingling across my chest and down both arms. I couldn't sleep at all, even though my son was a 'good sleeper'. I stopped eating. I really felt I could not cope with the baby and dreaded hearing his cries; I ended up in Accident and Emergency, where I saw an extremely helpful psychiatric duty nurse who encouraged me to get home visits from the psychiatric nurse team. This was helpful or extremely unhelpful depending on the nurses who visited! One told me to just ping a rubber band when I felt a panic attack coming on, but two others were sympathetic, practical and kept reassuring me that I would get better, which my psychiatrist also emphasised, but which I could hardly believe.

Vignette: (*Continued*)

Over Christmas, the pattern continued, although by late afternoon every day I would feel a bit better and would eat something. Writing about it now, 2 years on, is still painful: I felt I was going to end up in a secure unit and that the family would be better off without me (but I didn't self-harm). What I could do was breastfeed and cuddle my son – I did feel a bond with him immediately. It was my daughter's behaviour and needs that I found almost impossible to cope with or address; the need to run away was intense.

As with my previous postnatal depression 5 years earlier, memories of my recovery are very blurred. Being able to see my psychiatrist made a huge difference, as did her reassurance that I was being a 'good enough' mother, who had made an informed choice to take antidepressants while breastfeeding. Although I felt hopeless for a long time, particularly in the mornings, I kept going and was very frank about how I was feeling (too frank for a lot of people). I think having to care for my mother on a regular basis forced me to go out and to drive: as the small achievements built up and the medication began to work, I started to feel better. Another factor in my recovery this time was that, after an 18-month wait, I began CBT about 2 months after my son's birth. This has been hugely helpful, especially in helping to stop the almost constant self-criticism that became all-pervasive during my illness. I went back to the gym and made the effort to socialise with other mums. By early summer 2004, I was beginning to enjoy both children and was able to plan for the future. The summer holidays, with my daughter off school, my son nearly walking and me not due back at work until mid-September, were happy.

4.3.4   Psychosis

Psychosis in the early postnatal period (up to 3 months after delivery) is often termed puerperal psychosis. However, whether it is a distinct diagnosis is unclear. DSM-IV does not categorise puerperal psychosis as a separate entity and uses a postnatal onset specifier, while ICD-10 has a special category (though advises against its use). However, there appears to be an increase in rates of psychosis in the first 90 days after delivery. A study of admissions for psychosis within 90 days of delivery found 21-fold higher rates in this period compared with other times, with figures of around 1 per 1,000 (Kendell *et al.*, 1987), which were supported by a more recent study (Munk-Olsen *et al.*, 2006).

The incidence of puerperal psychosis is also unclear, partly because many studies included episodes of bipolar disorder that may not have been psychotic (Harlow *et al.*, 2007).

The incidence rate commonly quoted is 1 to 2 per 1,000 deliveries, although it has been suggested that if more stringent criteria are applied, such as admission with definite psychotic symptoms within 2 weeks of delivery, the rate is between 0.5 and 1 per 1,000 deliveries (Kumar, 1989; Terp & Mortensen, 1998). A later study of 502,767 first-time mothers found an average rate of 0.68 per 1,000 (Nager *et al.*, 2005). This study excluded those with an admission for psychotic disorder within 2 years before delivery. This would have removed those with existing serious mental disorder liable to relapse and thus indicates that childbirth is a risk factor for the onset of psychosis, albeit a very small one. These studies illustrate how the search for 'pure postnatal' conditions has complicated and hampered research into the course and characteristics of antenatal and postnatal mental illness.

Many women admitted with psychosis in the postnatal period have a pre-existing mental disorder, including bipolar disorder and schizophrenia. Indeed, some have suggested that new-onset psychosis of the postnatal period is essentially synonymous with bipolar disorder but, although bipolar disorder confers a much higher risk of puerperal psychosis, this does not seem to be the case (Dean *et al.*, 1989). However, a number of puerperal psychoses do appear to be episodes of existing disorder (see Chapter 5).

Vignette: A woman with no history of mental health problems who went on to develop psychosis after the birth of her three children

Prior to the birth of my children, I had no experience of mental health difficulties, apart from the great shock and grief I experienced at the sudden death of my mother, when I had to be put under sedation. I positively 'bloomed' throughout my three pregnancies and was totally unprepared for what was to hit me when I experienced psychosis for the first time.

My mental distress began in hospital after the birth of my first child. I had an emergency caesarean section following a long labour. An attack of breathlessness within 48 hours of the birth led to me being put on a course of heparin, which soon caused profuse bleeding as the result of a small artery not being tied during surgery. I lost a lot of blood, and my deathly paleness and inability to move very far, or care for my baby without feeling as if I was going to collapse, caused me great anxiety. I was worried that I was going to die and leave my son motherless. No one explained the extent of my anaemia; I was simply told that I'd feel better when I'd had a transfusion, which could not be done until I had come off the heparin. My anxiety increased as the days went by, a situation that was exacerbated by some nurses mocking me because I could not 'cope'. I felt that I was a hopeless mother and I slipped further and further into depression. Not being able to relax or sleep, and feeling continually anxious, the days seemed like weeks.

Vignette: (*Continued*)

Left alone in a side ward for much of the day, I sought comfort in my thoughts. I began to think of my mother and imagined that I could hear her talking to me. The imagined gradually became 'real'. Soon I could 'hear' more voices. I thought that doctors and nurses were talking about my condition and that I was probably going to die.

After the transfusion, the anxiety and depression remained. I woke on two successive nights having wet the bed, something which raised my anxiety levels still further. A lovely night nurse told me that I had been given largactil, and this had caused me to wet the bed – I had no idea. I refused to take the 'white tablets' when attempts were made to administer them the next day; my mistrust heightened. All I wanted to do was go home with my baby. My anxiety turned to frustration and anger, such that I was unable to relax or sleep. I was visited by two psychiatrists and was eventually allowed home.

At last I had escaped, but, on arriving home, I entered a manic phase. I was very relieved to be home and could not control my excitement. I talked non-stop about my experiences in 'that place' and was unable to sleep or keep still for more than a few minutes. Normally quite a modest person, I was now full of my own importance. The 'voices' returned and I began to think I had super powers. My husband called our GP, who in turn called in a psychiatrist. I was put on an antipsychotic and became 'zombified', neither my husband nor I having any idea of the side effects. I shuffled around the house, unable to stand upright or lift my feet properly. Within a few days, I was admitted to a general ward of a local psychiatric hospital. My son was sent off to be cared for by my sister-in-law, as my husband had to return to work and he had been told that I would be in hospital for 2 months.

On arrival at the hospital, I became very confused. I did not know why I was there and thought that perhaps I was going to help with the patients (I had worked as a ward orderly/cleaner on a psychiatric ward whilst I was at college). I kept asking for my baby and, after a few days, I was allowed to have him with me in a side ward. He slept in his pram; however, I found it very difficult to look after him due to the effects of the antipsychotic. Even lifting him from his pram and trying to feed him demanded a lot of effort. The psychiatrists told my husband that I was suffering from manic puerperal psychosis and that I should be given electroconvulsive therapy (ECT), but my husband refused to let them administer it. He had witnessed the dire after effects of the treatment in a colleague with whom he'd worked closely.

I told a psychiatrist that I felt weak and was experiencing difficulty in lifting my son, let alone holding him to feed him. It was then that I was told that this was

Continued

Vignette: (*Continued*)

> one of the effects of the drug. Over the next few days, my dosage was rapidly reduced, and I began to feel much more in control of myself, trying to keep myself busy by doing things for my son and helping on the ward. I had been on the ward for about a week when a new patient arrived who kept pestering me, wanting to pick up my son and do things for him. I was frightened that she would harm him, so I rang my husband and asked him to take our baby away from the hospital. I was rapidly discharged and went home with both of them. At home, my husband stayed with me for the first week. My GP and midwife visited me every day and friends gave terrific support. I battled with my mind and my restless body and was off medication after about 6 weeks.

4.3.5   Clinical practice recommendations

4.3.5.1   Women with an existing mental disorder who are pregnant or planning a pregnancy, and women who develop a mental disorder during pregnancy or the postnatal period, should be given culturally sensitive information at each stage of assessment, diagnosis, course and treatment about the impact of the disorder and its treatment on their health and the health of their fetus or child. This information should cover the proper use and likely side effects of medication.

4.3.5.2   Healthcare professionals should ensure that adequate systems are in place to ensure continuity of care and effective transfer of information, to reduce the need for multiple assessments.

4.3.5.3   Healthcare professionals should assess and, where appropriate address, the needs of the partner, family members and carers of a woman with a mental disorder during pregnancy and the postnatal period, including:
● the welfare of the infant, and other dependent children and adults
● the impact of any mental disorder on relationships with her partner, family members and carers.

4.4   AETIOLOGY OF ANTENATAL AND POSTNATAL MENTAL DISORDERS

The variation in the presentation, course and outcomes of mental disorders in the perinatal period is reflected in the breadth of theoretical explanations for their aetiology, including genetic, biochemical and endocrine, psychological and social factors. This reflects the complex aetiologies of these disorders and the social, psychological and biological changes occurring during this period. A review of the influences of these perinatal factors on mental illness is beyond the scope of this document. Much research has been undertaken to try to identify the aetiological factors that have a

significant influence, but at present this research has yielded little that has a significant impact on the treatment of mental illness at this time. As for specific factors connected to the perinatal period, the predominant specific hypothesis has been that hormonal changes in pregnancy and the postnatal period may be important (including thyroid and pituitary hormones, cortisol and gonadal hormones) but no clear aetiological association has emerged (Hendrick *et al.*, 1998).

4.5 CONSEQUENCES OF MENTAL DISORDER DURING PREGNANCY AND THE POSTNATAL PERIOD

All pregnancies carry risk, in particular to the fetus, with a base rate of obstetric risk and risks of congenital malformation of between 2 and 4% (that is, between 20 and 40 in 1,000) for the general population (Brockington, 1996). These risks increase where the woman has a mental disorder and there is evidence that mental disorder during this period can have a significant detrimental impact on the well-being of the woman, the fetus and the infant. For example, severe depression is associated with an increased rate of obstetric complications, still birth, suicide attempts, postnatal specialist care for the infant and low birthweight infants (Bonari *et al.*, 2004; Lobel *et al.*, 1992; Lou *et al.*, 1994; Wadhwa *et al.*, 1993). In schizophrenia and bipolar disorder, there is an increased rate of suicide and potentially significant exacerbation of the disorder if not treated, and poorer obstetric outcomes, including increased preterm delivery (Lewis & Drife, 2004; Hedegaard *et al.*, 1993; Nordentoft *et al.*, 1996), low-birthweight infants and infants who are small for gestational age (Howard, 2005; Jablensky *et al.*, 2005). Similarly, poor fetal outcomes have been associated with maternal eating disorders during pregnancy (Kouba *et al.*, 2005).

Maternal psychoses, including schizophrenia, appear to increase the risk of infant mortality (for example, Howard, 2005) and stillbirth (Webb *et al.*, 2005), although some research studies found no significant difference in rates between offspring of mothers with schizophrenia or bipolar disorder and those of other mothers (Jablensky *et al.*, 2005). Elevated risks of sudden infant death syndrome have also been reported in relation to postnatal depression (Mitchell *et al.*, 1992; Sanderson *et al.*, 2002) and to maternal schizophrenia (Bennedsen *et al.*, 2001).

There is also emerging evidence that untreated mental disorder in pregnancy may be associated with poorer long-term outcomes for children beyond the immediate postnatal period (Nulman *et al.*, 2002). For example, maternal depression postnatally may be associated with cognitive delay, as well as a range of emotional and behavioural difficulties in young children. Maternal schizophrenia is associated with significant parenting difficulties, with a high proportion of women losing care of their infant and poor outcomes for the mental health of offspring (Beardslee *et al.*, 1983; Rubovits, 1996). Schizophrenia may also affect a woman's ability to care adequately for her children more than other severe disorders (Hipwell & Kumar, 1996). Coupled with the direct effects of maternal mental illness on the infant, there are important indirect effects such as the social isolation and other disadvantages known to be associated with severe mental illness. All of these factors point to the importance of

appropriate treatment of the woman during pregnancy and the woman and the infant in the postnatal period.

Both psychological and pharmacological treatments are effective in the treatment of most major mental disorders (NICE, 2002, 2004a, 2004b, 2004c, 2005a). For a proportion of women, pharmacological treatments may be the treatment both advocated by a healthcare professional and chosen by the woman herself, but this can itself carry a potential risk to the infant. However, the risks associated with most psychotropic drug exposure in pregnancy and breastfeeding are not well understood (Patton *et al.*, 2002). For women and clinicians, the assessment of drug treatment risk is therefore highly complex and further complicated by the need to balance this against the harm of untreated disorder. The processes, and the skills needed for communicating and discussing these risks and benefits to patients, are also not well developed (Epstein *et al.*, 2004; Scialli, 2005). Furthermore, individual variation in the assessment and perception of risk are rarely acknowledged or measured. In addition to possible teratogenic and other risks to the fetus, the altered physical state of the woman over the course of a pregnancy means that increased physical monitoring, for example blood glucose during pregnancy, the impact of analgesic drugs during delivery and the impact on breastfeeding, all need to be considered in decisions about pharmacological treatment. These issues are discussed more fully in Chapter 7.

4.5.1   Consequences for the woman

For a woman who develops a mental disorder, either antenatally or postnatally, there is an additional burden to the suffering arising specifically from the disorder. The woman is very often concerned that her mental health problems may prevent her from actively caring for herself, the unborn child or the infant. This can exacerbate an already troubling and disabling disorder. Mental disorder, particularly in its more severe form, is also associated with significant impairment in social and personal functioning. The extent of this impairment may have a significant effect on the woman's ability to care effectively for herself and her children. The impact of this can most obviously and tragically be seen in the significant number of women with schizophrenia who lose custody of their children (Howard, 2005). The long-term effects of this on the woman are considerable.

4.5.2   Consequences for the infant and sibling

The impact of a maternal mental disorder can affect the social and cognitive development of children (for example, Murray *et al.*, 1996; Hay *et al.*, 2001) and can also have long-term consequences on their mental health (Beardslee *et al.*, 1983; Rubovits, 1996). Problems can be long term; for example, both behavioural problems and impaired cognitive outcome up to 7 years of age have been reported (Huizink *et al.*, 2003; O'Conner *et al.*, 2003; Van den Bergh *et al.*, 2005). Reduced IQ in children (particularly boys) aged 11 years whose mothers had depression early in the

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postnatal period has also been demonstrated (Hay *et al.*, 2001). The negative impact on mental health, however, is not the only area of concern and children of women with significant mental health problems may also be at risk of physical health problems. In a very small number of cases, this can lead to considerable neglect of the child and active physical abuse, with occasionally tragic consequences.

4.5.3 Consequences for the wider family

Mental health problems in pregnancy also present a burden to the wider family, not just the children and siblings. This can be seen in the difficulties faced by partners (Lovestone & Kumar, 1993), which have implications not just for the physical health and well-being of individuals but may also have a significant impact on their socio-economic situation.

Vignette: A woman with depression and self-harming behaviour in the postnatal period

I think I have always suffered from depressive tendencies, especially during my teenage years and around my menstrual cycle. When I was 15, my mum found out that I was self-harming and she took me to see a doctor. I was living with my father at the time and when we moved it was not followed up by another doctor because my father thought I was doing it for attention.

But what I suffered was nothing compared with how low I got after my son was born in December 2003. During my pregnancy, I was very sick and extremely tired and I had to take a lot of time off work. There were days when I could not even make it out of bed. The more time I had off work, the more time I had to think and worry. I began to get very low.

My midwife was great. I broke down on her and was able to tell her how I was feeling. I was so scared about being a mum and how I thought I wouldn't be able to cope. I would have appointments with her regularly to keep a check on my emotional state and I was referred to the psychiatric assessment unit at my local hospital.

I had the assessment while I was still pregnant; it was horrible. Two men asked me all sorts of questions that were not related to how I was feeling. I felt very tense and uncomfortable and like a fake who was wasting their time. Then, after 45 minutes, they said that there was nothing wrong with me, that it was just in my personality and that I would have to live with it. I was devastated because I knew that something wasn't right, but no one listened. I tried to ignore my feelings because, after all, they were professionals, had studied for years and

Vignette: (*Continued*)

had to be right. They did, however, set me up with a floating support worker to help me once the baby was born.

I had a normal delivery and my baby was very healthy. I remember constantly crying in hospital, but everyone said it was normal baby blues that would soon wear off in a few days. My son was born a week before Christmas, so the first few weeks of his life were very hectic with people visiting. I think I went into over-drive at this point. I was breastfeeding every 3 to 4 hours on demand and through the night, which was very physically draining. A health visitor and my family told me to introduce formula milk but I refused to stop breastfeeding; it was the only thing I could offer my son that no one else could. I was struggling to bond with my son, and I felt that if I gave up breastfeeding then I would have failed him. I had to do what I thought was right. During this period, I could not sleep and when my son slept I couldn't relax – there was so much to do. I had to be a good mum. I had to get everything just right. If I did sit down I would panic that my baby was ill or that he would wake up and need something that I couldn't offer him.

I was seeing my support worker once a week and she tried to put my mind at rest, but I was very afraid to express how bad I really felt in case Social Services were called. I covered up how I truly felt because if I did mention my feelings to anyone or asked for help they just told me to give it time, that it takes a while to adjust and that it was just baby blues and would go away in a few days.

Once life settled down again, cracks in my relationship with my son's father started to show. We were arguing all the time. I began to get very low. My support worker and my health visitor started to notice, but I didn't want to admit anything, so I covered my feelings up. I was worried that if I told anyone exactly how I felt my son would be taken into care. I did see the doctor and he prescribed antidepressants (including a tricyclic antidepressant [TCA] and a selective serotonin reuptake inhibitor [SSRI]) to lift my mood. I was also given a hypnotic and a benzodiazepine.

When my son was about 3 months old, his father left; he could no longer cope with me constantly crying. He said some awful things about how I had made him miser-able and that I was failing as a mother, which just fed into my guilt and finally tipped me over the edge. I began self-harming, which was something I hadn't done since I was 15. It felt like I was in a black hole and couldn't get out. I even had suicidal thoughts and I believed that everyone would be better off without me. But I couldn't act on the thoughts – all I could think about was my son and how I couldn't put him through that. It wasn't his fault that I felt this way, but every time I looked at him he reminded me of his father and how much he had hurt me. I cared about my son but didn't feel like he was mine. I felt that I couldn't be a mum – I

Vignette: (*Continued*)

was young (23) and didn't want the responsibility. I couldn't connect with the fact he had been in my tummy and I would have flashbacks of his birth. Now he looked to me for everything – he was totally dependent on me and I could hardly look after myself. I was forgetting to eat and struggling to do anything. How could I love someone who caused this? If I hadn't accidentally fallen pregnant, I wouldn't be depressed. I hated myself for feeling, let alone thinking, those things.

I went to the doctor and he sent me to Accident and Emergency straight away for another psychiatric assessment. I had to wait 6 hours to see the on-call psychiatrist. It was very scary and upsetting: I thought I was mad and they were going to section me. They said I was suffering severe sleep deprivation and post-natal depression. I was given sleeping tablets and referred to a crisis team. The crisis team was not much help; in fact, one lady who came to visit me was terri-ble. She talked to me as if I was stupid, told me to pull myself together and laughed at the fact I self-harmed. My mum, who had come to look after me, nearly threw her out of the house. We asked not to see the team again. I stayed at my auntie's house – my family were too scared to leave me alone as my self-harming started to reach desperate levels.

Finally, my cousin, who came with me to another psychiatric assessment, told the doctors that no one could cope with me and that everyone was so worried I would harm my son or commit suicide. She had to beg for help before someone would do something. I was admitted to the mother and baby unit (MBU) of a psychiatric hospital, where I stayed for over 6 weeks. My son was by my side the whole time. My medication was changed because I was breastfeeding and finally the migraines that I had been suffering from stopped.

Having people around really helped, especially meeting other sufferers. I had been beginning to think I was going insane and I was the only one who had ever felt like this, so it was good to know I wasn't the only one. The nurses were very sympathetic and helpful; they explained what was happening to me and ways to cope without self-harming. The occupational therapist suggested hobbies that kept my mind busy and used my hands, like knitting and art work. The physio-therapist suggested relaxation techniques like meditation and visualisations, and the nurses suggested distraction such as having a bath and reading. Best of all, I found writing down my feelings helped. I was able to express myself without upsetting any one and it cleared my head.

As my son was older than the other children (he was about 7 months old at this time), he slept in my room at night unlike the younger babies that slept in the nursery, but someone was always around if you had a problem. I do believe I would not be here today if I had not been admitted.

4.6 TREATMENT IN THE NHS

In common with mental disorders at other stages in people's lives, detection by different professionals is variable, and this inevitably results in reduced treatment for perinatal disorders. Stigma and concerns about potential statutory involvement in the care of the infant may add to the reluctance to seek help, even where it is recognised by the woman herself. The detection of mental disorders in the perinatal period is the subject of Chapter 5 and will not be discussed in detail here. However, an idea of the consequences of under-detection can be obtained from the detection of depression in the general population. Of the 130 cases of depression per 1,000 population, only 80 will consult their GP. Of the 80 depressed people per 1,000 population who do consult their GP, 49 are not recognised as depressed, mainly because most such patients are consulting for a somatic symptom and do not consider themselves mentally unwell, despite the presence of symptoms of depression (Kisely *et al.*, 1995). This group also has milder illnesses (Goldberg *et al.*, 1998; Thompson *et al.*, 2001). GPs and other non-mental-health specialists are immensely variable in their ability to recognise depressive illnesses, with some recognising virtually all the patients found to be depressed at independent research interview and others recognising very few (Goldberg & Huxley, 1992; Üstün & Sartorius, 1995).

The communication skills of healthcare professionals make a vital contribution to determining their ability to detect emotional distress, and those with superior skills allow their patients to show more evidence of distress during their interviews, thus making detection easy. Those with poor communication skills are more likely to collude with their patients, who may not themselves wish to complain of their distress unless they are asked directly about it (Goldberg & Bridges, 1988; Goldberg *et al.*, 1993).

In summary, those with more severe disorders, and those presenting psychological symptoms, are especially likely to be recognised, while those presenting with somatic symptoms for which no cause can be found are less likely to be recognised. It is probable that the position described above for depression holds for most, if not all, mental disorders. Antenatally and postnatally, women are in frequent contact with healthcare professionals, which provides opportunities for increasing healthcare professionals'awareness of mental health problems and improving their detection skills.

4.6.1 The provision of care for perinatal disorders in the NHS in England and Wales

As with most common mental health problems, the large majority of women (over 90%) with perinatal disorders are treated in primary care. The remainder receive care from specialist mental health services, including general adult services, liaison services and specialist perinatal services. The current provision of specialised antenatal

and postnatal mental health services in primary and secondary care is covered in Chapter 8.

4.6.2 Pharmacological treatments

There is little evidence to suggest that pharmacological treatments (the mainstay of treatment of mental disorders in the NHS) have any differential benefit in pregnancy or the postnatal period from their use in other adult populations. The major difference in the perinatal period (and for some women pre-conceptually) is in the shifting risk-benefit ratio in pregnancy and the postnatal period. This relates to the increased risk to the fetus (and subsequently the infant when breastfeeding) arising from the possible teratogenic and neurodevelopmental risks associated with the use of psychotropic medication. The risks are relative and need to be balanced carefully in the case of each woman and set against the baseline risks of malformation, the likely benefits of any treatment and the risks of untreated mental disorder that increase the baseline risk of malformations. Clinicians also need to be aware of potential changes in the pharmacokinetics of drugs in pregnant women due to increased fluid balance, particularly in the third trimester. Women may also be less able to tolerate some side effects during pregnancy or the postnatal period.

4.6.3 Psychological treatments

As with pharmacological treatments, there is little evidence, other than in the treatment of depression, on the differential effectiveness of psychological treatments during pregnancy and the postnatal period. Again, it is the changing risk–benefit ratio, in particular the cost–benefit ratio, that influences the use of treatments. For example, in the NICE depression guideline (NICE, 2004a) antidepressants were recommended before psychological treatments (on cost-effectiveness grounds) for the treatment of moderate depression, but this position may change when the possible harms associated with the issue of antidepressants are taken into account (see Chapter 7). In addition, many women are reluctant to take drugs during pregnancy. Given the limited availability of psychological treatments, this may present a considerable challenge for perinatal services (DH, 2004).

4.6.4 The organisation of perinatal mental health services

The organisation of perinatal services does not follow any consistent pattern across England and Wales; provision is variable, recommendations from various sources are often not coordinated (DH 2004, 2002; Mann, 1999), and none provides recommendations for the full range of services across primary and secondary care. The service

structures required to support effective antenatal and postnatal mental healthcare are discussed in Chapter 8.
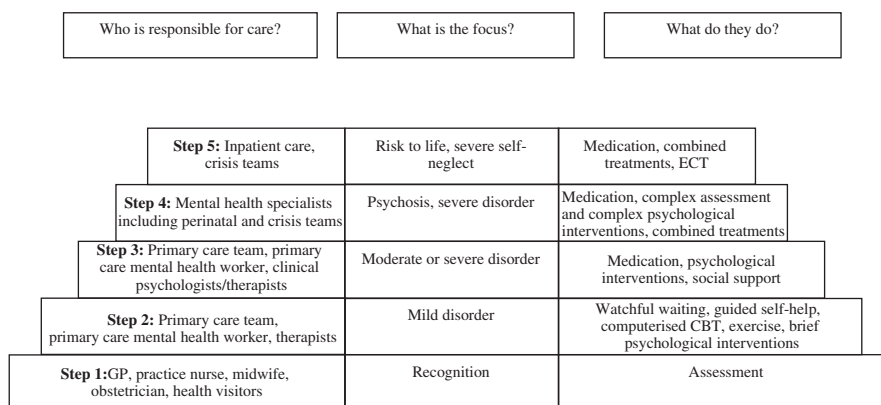
One challenge faced by those involved in the care of women with antenatal and postnatal mental health problems is the wide range of services that women use at this time. This requires close communication and agreed plans of care at the level of the individual woman and for effective collaborative working arrangements at a service level between primary care (GP, health visitor and counsellor), maternity services (midwife and obstetrician) and, where appropriate, secondary care mental health services and also social services and the independent and voluntary sectors. This network of care must not only consider the needs of the woman and her child but also other family member and carers. Poor communication has often been identified as the reason for poor-quality care and was behind the development of the care programme approach in the UK healthcare system (DH 1999).

In addition to providing effective communication, services need to be organised in ways that promote the development of cost-effective treatments and provide clear pathways, which are understandable to both providers and recipients of care. The experience for the individual woman of the involvement of multiple professionals can be bewildering and overwhelming. If not properly coordinated to prevent duplication, overlaps and gaps in service, this may also be counter-therapeutic. Despite the involvement of multiple services, it can be women's experience that their needs for practical help at this critical time are neglected because services tend to emphasise processes of assessment, monitoring, psychotherapeutic intervention and medication but rarely address the practical demands of looking after one or more young children day and night while mentally unwell.

In a number of the NICE guidelines, a 'stepped' or 'tiered care' model of service delivery has been developed, which draws attention to the different needs that women with antenatal and postnatal mental health problems have, depending on the characteristics of their problem and their personal and social circumstances, and the responses that are required from services. This stepped/tiered model is a hybrid of two ideas. At one end, is 'pure' stepped care where people are offered the least intrusive and lowest intensity intervention likely to be effective in helping them. They would only receive a more intensive, or complex, intervention if they failed to improve at an earlier step. At the other end, there is stratified care where often the intervention is linked to a particular diagnosis or service provider. Patients are directed to the service or professional who is seen to provide the optimum intervention for that person. Both these models are sometimes 'overlaid' onto a service model that identifies various tiers of services often provided by different organisations. The model also assumes effective working relationships across the system; for example, a specialist mental health or perinatal service may provide advice, training or consultation on the management of patients at levels one and two.

There are advantages and disadvantages to each of these models. The following is a model that attempts to outline the relationship between severity of illness and the most appropriate professional skill set in the corresponding organisational structure (see Figure 4). It should be used, as all models should, as an aid to thinking rather than a concrete set of proposals for who does what.

Figure 4: The stepped/tiered care model

Who is responsible for care?	What is the focus?	What do they do?

Step 5: Inpatient care, crisis teams	Risk to life, severe self-neglect	Medication, combined treatments, ECT
Step 4: Mental health specialists including perinatal and crisis teams	Psychosis, severe disorder	Medication, complex assessment and complex psychological interventions, combined treatments
Step 3: Primary care team, primary care mental health worker, clinical psychologists/therapists	Moderate or severe disorder	Medication, psychological interventions, social support
Step 2: Primary care team, primary care mental health worker, therapists	Mild disorder	Watchful waiting, guided self-help, computerised CBT, exercise, brief psychological interventions
Step 1: GP, practice nurse, midwife, obstetrician, health visitors	Recognition	Assessment

4.7 THE ECONOMIC BURDEN OF MENTAL DISORDERS IN THE ANTENATAL AND POSTNATAL PERIOD

Existing evidence on the financial implications of the presence of mental disorders in women who are pregnant or in their first postnatal year is very limited. A systematic review of the literature identified three studies that explored the additional healthcare resource use and/or financial costs associated with care of women with postnatal depression and their infants. No studies examining the economic burden imposed by women with other mental health disorders during the antenatal and postnatal period were found in the literature.

Petrou and colleagues (2002) estimated the health and social service costs of postnatal depression in a cohort of 206 women at high risk of developing the condition. The study was conducted in Reading from May 1997 to April 1999. Women were identified as being at high risk using a predictive index for postnatal depression. Costs were estimated for participating women and their infants over 18 months postnatally and included costs of inpatient, outpatient, day care and community services. Paediatric and childcare services were recorded separately.

The mean mother-infant dyad costs over 18 months were found to be £2,419 when women developed postnatal depression (according to SCID-II) and £2,027 when no postnatal depression was diagnosed (2000 prices). The overall cost difference between the two groups was non-significant (ΔC = £392, p = 0.17); however, the community care costs for women with postnatal depression were significantly higher compared with respective costs for women without postnatal depression (p = 0.01). The authors estimated that, with approximately 700,000 women giving birth in the UK annually and a 13% incidence of postnatal depression, the economic burden of this condition to the health and social services in the UK amounted to roughly £35.7 million annually (range £34.4 to £43.3 million, 2000 prices). It was acknowledged that this value might in reality be a conservative estimate, given that the condition was likely to have longer-term consequences in terms of health status and health service utilisation over the woman's and infant's lifetime and in terms of the child's

educational requirements. Moreover, with evidence that women not at high risk for postnatal depression had fewer antenatal and postnatal contacts than the study population, the additional costs associated with care of women developing postnatal depression might be even higher in comparison to respective costs associated with care of the population of women giving birth as a whole.

Another study conducted in Canada estimated the average costs of care (health and social services) for women and infants in the first 4 weeks postnatally (Roberts *et al.*, 2001). The analysis was based on a cross-sectional survey of 1,250 mothers of normal newborn infants. Women were assessed for depression using the EPDS. Cases of depression were defined by an EPDS score ≥ 12. The total cost of health and social care over 4 weeks postnatally was \$845 for women with depressive symptomatology and their infants versus \$413 for those not depressed (Canadian dollars, $p < 0.01$). The total mother-infant dyad cost was \$2,137 when women had very high scores (EPDS > 19) versus \$434 when women were depressed but with an EPDS score of ≤ 19. Medical costs were similar for depressed and non-depressed women; however, paediatrician, community nursing and social work costs were significantly higher per mother-infant dyad when women were diagnosed with depression.

Comparable findings were reported in an Australian study by Webster and colleagues (2001). The objective of the study was to compare health and social care use and satisfaction with services between depressed (EPDS ≥ 12) and non-depressed women in the first 4 months postnatally. Data on 574 mother-infant dyads demonstrated that depressed women were more likely to visit a psychiatrist, postnatal depression group, social worker, paediatrician or GP than non-depressed women. Overall, depression led to an increased use of health and social care services and had a negative effect on satisfaction with some of the services provided.

Besides the costs reported in the above studies, one also needs to consider the long-term costs of care for infants born to mothers with mental disorders, including costs associated with management of the cognitive and behavioural problems these infants face in the future (Huizink *et al.*, 2003; O'Connor *et al.*, 2003b; Van den Bergh *et al.*, 2005), as well as costs of care for children neglected or abused because of their mothers' psychological condition. In addition to the financial cost to health and social services, there is some preliminary evidence that postnatal depression places substantial extra burdens on fathers/partners and close family members, causing financial problems within the family (Boath *et al.*, 1998). Although the available evidence is very limited and focuses on postnatal depression, it demonstrates that mental disorders during the antenatal and postnatal period, besides the established psychological and social implications for the women, their infants, and the wider family, also place a considerable financial burden to health and social services and to society as a whole.

4.8 EXPLAINING RISK TO WOMEN: HELPING PATIENTS TO MAKE DECISIONS ABOUT TREATMENT

Women may feel disempowered by being pregnant or caring for a newborn infant at the same time as requiring treatment for a mental illness. Therefore, enabling them to

express their views and make choices is important. In order to help women make informed decisions about their treatment, it is vital that healthcare professionals explain the risks of different treatment options accurately, balanced against the risk of not treating mental disorder. The risks that must be taken into account include:

1) **Existing risk to the fetus:** the background risk in the general population of a fetus developing a minor or major malformation is around 2% to 4% (that is, 20 to 40 in 1,000) (Brent & Beckman, 1990; Brockington, 1996).

2) **Risk of not treating mental disorder:** the risks of not treating mental disorder depend on the disorder in question and the woman's psychiatric history. However, not treating the disorder poses a risk both to the woman's physical health as well as her ongoing mental health and well-being. There is also risk to the fetus and infant from untreated disorders and there may be risks to family, fathers/partners and carers.

3) **Risk of treating the disorder:** the risks of treating the woman's mental health problem with psychotropic medication include side effects for the woman and possible malformation or developmental problems for the fetus, such as neurobehavioural teratogenicity. This varies between different drugs and, in some cases, is dose dependent. There are also risks for the infant immediately after delivery, including withdrawal effects and toxicity.

These factors need to be considered within the context of the woman's current situation, including an appraisal of her coping resources, past illness and pregnancy experiences, and current lifestyle and family situation, such as having other children to care for. This section discusses patient participation in the decision-making process and methods for explaining risks to patients.

4.8.1 Patient preference in decision making

Given the potential risks involved during pregnancy and the postnatal period for women with mental health problems, it is vitally important that women are fully involved in treatment decisions, since even accurate individual risks have a different subjective significance to different women. For example, a high risk of becoming ill may be less important to a woman than a very small risk of a fetal malformation, whereas for another woman even a small risk of an episode of what has been a very severe illness in the past may be unacceptable. However, some patients may not want to be involved to the same degree as others. A narrative review of studies examining factors affecting patient preference for involvement in medical decisions reported that preference was affected not only by factors such as age and education level (younger patients preferred a more active role, as did those with higher education), but also factors such as experience of being a patient, with some studies reporting that increased patient experience reduced the desire to be involved (Say *et al.*, 2006). However, the authors point out that it is not clear which is more important: experience of care or experience of illness. The review also reports that clinician behaviour may play a part in patient preference for involvement in decision making, with patients being more motivated to be involved

depending on factors including doctors' use of their first name and discussion of test or treatment results. Say and colleagues (2006) also reviewed qualitative studies that supported these findings, with patients who experienced good relationships with clinicians finding it easier to be involved in the decision-making process. However, the review of qualitative studies also found that patients may not understand information about risk and may find it hard to make choices when they have no experience of the potential consequences. Say and colleagues (2006) also report studies that found a fear of making the 'wrong' decision may discourage patients from participating. It should be noted that no study in this review (quantitative or qualitative) solely involved mental health patients, so these findings may not be generalisable to mental health settings.

Explaining risk is not easy. Few professionals are trained in how to understand and communicate risk effectively and few patients find it easy to fully understand or participate in risk conversations. A review by Thomson and colleagues (2005) considers the major issues involved and the current state of research in this area, an overview of which is described below.

4.8.2   Use of language

Use standardised language to convey the magnitude of risk, such as 'high/medium/ low' or 'probable/unlikely/rare', may be helpful, particularly where the precise risk is unknown (Thomson *et al.*, 2005 reporting on Fox & Irwin, 1998). However, the interpretation of these terms is likely to vary between individuals (Thomson *et al.*, 2005), and approaches such as quantifying terms – for example, 'high' for risks greater than 1 in 100 – have also been suggested (Calman & Royston, 1997), although there appears to be no evidence that this is helpful to patients. Similarly, putting the risk faced by the patient into the context of everyday life, for example, expressing a risk in terms such as 'this is equivalent to one person per family/street/town/country, and so on' has been suggested (Calman & Royston, 1997) or in terms of everyday examples, such as the likelihood of being struck by lightening. Although these approaches have some intuitive appeal, none has been tested empirically.

Unfortunately, the nature of most risks related to the harm of psychotropic medication is inherently uncertain, and it is important when discussing risks with patients to help them understand this. Using terms such as 'our best guess is . . .' may be helpful (Thomson *et al.*, 2005), as well as the other suggestions in this section.

4.8.3   Discussing rates and the reference class

Use the natural frequency – avoid percentages
The natural frequency of an event (that is, the actual number likely to be at risk per appropriate denominator) is less likely to be misinterpreted than percentages. For example, Gigerenzer and Edwards (2003) describe a doctor who explained to his patients that taking fluoxetine resulted in a 30% to 50% chance of sexual problems. His patients thought he meant that 30% to 50% of sexual encounters would go awry,

whereas in fact the doctor meant that, of 10 patients taking fluoxetine, 3 to 5 would have a sexual problem. Similarly, clinicians also find it hard to understand how to interpret data correctly. In a study, the number of physicians correctly calculating the correct number of people with cancer given data as probabilities (as a percentage) was far lower than those given the data as natural frequencies (numbers out of 10,000) (Hoffrage & Gigerenzer, 1998). See Box 1 for an example problem.

Use absolute rather than relative risks
Percentages are also misleading because they reflect relative statistics; for example, a 25% reduction in breast cancer survival rate, may actually reflect reduction from 4 in 1,000 to 3 in 1,000.
   Natural frequencies are easier to understand because they carry implicit information about base rates and reduce the number of computations required to do the calculation.

Make the baseline clear
Similarly, when describing an event such as the possibility of having a stroke, using a clear reference group makes the statistics easier to understand – for example, 'Of 100 people like you, five will have a stroke in the next year' is easier to understand than 'you have a 5% chance of having a stroke in the next year' (Thomson *et al.*, 2005).

Avoid mixing denominators
It is less confusing to say '89 in 100 will get better but 4 in 100 will experience a serious side effect' than '89 in very 100 will get better but one in 25 will experience a serious side effect' (Thomson *et al.*, 2005; Grimes & Snively, 1999).

Box 1: Examples of clinical problems with probabilities and with natural frequencies [reproduced without permission]

A blood test that can be carried out in a GP's surgery has been devised to help diagnose a disease that has few early symptoms, but can be fatal. The disease most commonly occurs in people over the age of 55. Patients who test positive are sent for further tests. You are a GP and you want to know how likely it is that a patient who has tested positive actually has the disease. The following information is available:

Probabilities
The probability that people over the age of 55 have the disease is 0.3%. If one of these people has the disease, the probability is 50% that he or she will have a positive test. If one of these people does <u>not</u> have the disease, the probability is 3% that he or she will still have a positive test. Imagine a person (aged over 55, no symptoms) who has a positive test in your screening. What is the probability that this person actually has the disease? _____ %

Natural frequencies
Thirty out of every 10,000 people over the age of 55 have the disease. Of these 30 people with the disease, 15 will have a positive test. Of the remaining 9,970

Box 1: (*Continued*)

people <u>without</u> the disease, 300 will still have a positive test. Imagine a sample of people (aged over 55, no symptoms) who have positive tests in your screening. How many of these people actually do have the disease? ____ of ____

The correct answer is that 5% or 1 out of 21 of those with a positive test result will have the disease.

4.8.4   Framing

How risks are presented can also affect how they are interpreted. Another review found four studies (three RCTs and a quasi-experimental study) comparing positive framing (for example, chance of a good outcome) with negative framing (for example, chance of a bad outcome) in a clinical milieu (Edwards *et al.*, 2001). Rather than support the prediction that positively framed treatment options would be more favourably viewed than negatively framed options, no clear effect was found. However, the same review also found seven papers (six RCTs and one quasi-experimental study) comparing 'loss' framing with 'gain' framing (that is, information about the risks and disadvantages of a treatment option compared with information about the benefits). Only the RCTs reported clinical behaviour outcomes, one of which was concerned with prevention of illness (skin cancer) whereas the others (including the non-randomised controlled trial) were concerned with detecting disease. Edwards and colleagues (2001) found an effect for loss framing on increasing uptake of screening (odds ratio [OR] = 1.18 [95% CI 1.01, 1.38]).

4.8.5   Visual presentation

Various visual aids have been developed to present risks in a way that can be easily assimilated; however, these do not appear to have been tested empirically. Some are computer based, such as Chris Cates' Visual Rx program (available at www.nntonline.net), which converts user-input risk rates to 100 faces to illustrate the risks involved, including smiley faces for good outcomes and unhappy faces for poor outcomes. This can help put risks into perspective.

4.8.6   Individualised risk presentation: tailored probabilities

Many risks relevant to women taking psychotropic medication during pregnancy or breastfeeding are not only not accurately established, but also often expressed in terms of population rates rather than in terms of the risk for the individual. It is, however, helpful to personalise the risks involved for the individual patient (Thomson *et al.*, 2005), although the success of this depends on good quality data. A good example of how this approach can work is available on the Harvard Center for Cancer Prevention (www.yourdiseaserisk.harvard.edu), which covers several cancers, osteoporosis and stroke. However, such a system does not appear to be available in the area of antenatal and postnatal mental health.

4.8.7 Decision aids

A Cochrane review of decision aids (O'Connor *et al.*, 2003a), which attempted to draw up a comprehensive inventory of available aids in addition to reviewing RCTs evaluating decision aids, found 221 decision aids and 35 RCTs. The review found that decision aids helped to improve knowledge of options and outcomes and to generate more realistic expectations of the benefits and harms of outcomes. The decision aids found covered many areas of clinical practice, including treatment options for cancer, hypertension and osteoporosis, birth options post-caesarean, and screening for cancer. The review did not find any decision aids specifically designed for women making choices about psychotropic medication during pregnancy and breastfeeding.

4.8.8 Issues for research

There is little empirical work evaluating strategies for understanding and explaining risks to patients and none in the area of perinatal mental health. Of particular issue in research in this area is the definition of appropriate outcome variables. These could include behavioural or physical outcomes, such as relapse rate, adherence, cognitive outcomes such as knowledge and accuracy of risk perception, and affective outcomes such as satisfaction with communication or with the decision made (Thomson *et al*., 2005).

4.8.9 Clinical summary

Full discussion involving up-to-date information and joint decision making about all aspects of care is important, and professionals involved in such discussions must have appropriate skills in the communication, assessment and management of clinical risk. In particular:

● Clinicians need to display competence and care, and work to develop a trusting relationship with women. They need to have a willingness to explore the ideas, concerns and expectations of women and the ability to develop a partnership with them; understanding should be checked regularly.
● Clinicians need to discuss with women how much information they want about the risks and benefits of different treatment options and should enable women to feel as involved as they want to be with the right level of information and active decision making for them.
● Where possible, absolute risk values, natural frequencies and common denominators should be used.
● Decisions aids in a variety of formats, verbal and visual, including figures and images such as 'smiley faces', may be useful.
● Clinicians should aim to personalise the risks as far as possible, taking into account particular factors relating to the person to whom they are talking.
● Written material summarising the risk (individualised if possible) or, where possible, audiotaped records of the consultation should be made available to the women.

● Clinicians need to acknowledge the limits of both their knowledge and of what is known in the literature and explain the uncertainty surrounding an assessment of risk.

4.8.10 Clinical practice recommendations

4.8.10.1 Healthcare professionals should work to develop a trusting relationship with the woman, and where appropriate and acceptable to the woman, her partner and family members and carers. In particular, they should:
● explore the woman's ideas, concerns and expectations and regularly check her understanding of the issues
● discuss the level of involvement of the woman's partner, family members and carers, and their potential role in supporting the woman
● be sensitive to the issues of stigma and shame in relation to mental illness.
4.8.10.2 Before treatment decisions are made, healthcare professionals should discuss with the woman the absolute and relative risks associated with treating and not treating the mental disorder during pregnancy and the postnatal period. They should:
● acknowledge the uncertainty surrounding the risks
● explain the background risk of fetal malformations for pregnant women without a mental disorder
● describe risks using natural frequencies rather than percentages (for example, 1 in 10 rather than 10%) and common denominators (for example, 1 in 100 and 25 in 100, rather than 1 in 100 and 1 in 4)
● if possible use decision aids in a variety of verbal and visual formats that focus on an individualised view of the risks
● provide written material to explain the risks (preferably individualised) and, if possible, audio-taped records of the consultation.

4.8.11 Research recommendation

Decision aids for helping pregnant and breastfeeding women
make decisions about their care
An RCT should be conducted to compare usual care with usual care plus the use of decision aids designed to enable pregnant and breastfeeding women with mental disorders to make informed decisions about their care. Outcomes should include the development of agreed care plans, the successful implementation of the agreed care plans, and satisfaction with the care plan and the communication about the planning.

Why this is important
Psychotropic drugs carry teratogenic risk during pregnancy and are often present in breast milk. It is therefore important that women are enabled to make informed decisions about treatment choices.