Chapter 5 Psychosocial implications of MS

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5.1 INTRODUCTION

The impact of multiple sclerosis (MS) on the individual and their family is wide reaching and cannot be underestimated. Individuals respond both to diagnosis and disease progression in different ways, both positive and negative. These may include low self-esteem, depression and withdrawal, which can lead to increased stresses on close relationships. Many people also respond to the continued impact on their quality of life, e.g. social and financial status, employment and independence, in a similar way (Bradshaw et al, 1996). The precise relationships among quality of life, depression, fatigue and cognitive impairment in MS are complex and poorly understood (Patti et al, 2011).

Despite the abundance of literature on the psychosocial needs of individuals with MS and increased individual access to MS clinics and team interventions, the psychosocial component of individual care remains largely unattended to. A Canadian survey of 353 MS patients and 240 significant others, who completed a quantitative questionnaire on psychological and psychosocial needs confirm the high importance of psychological intervention in MS care (Bernbow & Koopman, 2003).

This weakness in adequately addressing the psychosocial needs of individuals with MS is evidenced by the lack of tools available for assessment of these issues. There are hundreds of articles on the importance of appropriate psychosocial assessment and intervention in MS.

Research suggests that using an orderly and systematic approach to assessing psychosocial problems, determining appropriate interventions, initiating a collaborative plan, and evaluating the efficacy of this plan can significantly increase individual adherence to therapy, improve self-care skills, and assist individuals in adapting to MS (Taylor 1987).

This chapter describes the wellness nursing process and proposes ways to assess and evaluate psychosocial problems related to a new diagnosis, sexuality, family issues, vocational and financial concerns. Plans and interventions for dealing with these issues are also discussed.
5.2 OVERVIEW

This chapter contains the following:

- The Wellness Model in MS nursing
- Nursing assessment
- Care plan for newly diagnosed individuals
- Sexuality, family issues and pregnancy
- Financial and vocational issues.

At the end of the chapter, please find a section entitled Progress check; this section tests your knowledge of the information presented in the chapter.

5.3 THE WELLNESS MODEL IN MS NURSING

5.3.1 Introduction

Due to the variable nature of MS and the uncertainty and loss of control associated with the disease, the MS nurse must develop dynamic interventions that meet each individual’s needs. Clark’s Wellness Model can assist nurses in this process. In the traditional nursing model, the nurse performs and the individual receives. The Wellness Model, on the other hand, promotes a partnership between the nurse and the person with MS; the goal of this partnership is to empower the person with MS to develop self-awareness and to take responsibility for their own health (Clark, 1986; Halper et al, 1997; Halper & Holland, 2011).

In this section, Clark’s Wellness Model is described and the implications of this model for the nursing process are discussed.

5.3.2 Learning objectives

After completing this section, the reader will be able to:

- Compare the wellness nursing process to the traditional nursing process
- Apply the wellness nursing process to his/her clinical practice
- Describe the roles of the various members of the multidisciplinary team involved in the care and treatment of persons with MS.
5.3.3 Clark’s Wellness Model

Because MS has no cure, the person with MS and their family, must assume ongoing responsibility for healthcare and self-monitoring (Halper & Holland, 2011). Clark’s Wellness Model promotes individual self-responsibility and emphasises “whole-person” wellness (see Table 5.1). In this model, a person can be ill but still have a deep appreciation for the joy of living.

Table 5.1. Comparison of the traditional nursing and wellness nursing processes. Adapted with permission from Halper et al, 1997 and Halper & Holland, 2011.

<table>
<thead>
<tr>
<th>TRADITIONAL NURSING PROCESS</th>
<th>WELLNESS NURSING PROCESS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess individual</td>
<td>Teach individual how to assess their own level of health</td>
</tr>
<tr>
<td>Diagnose</td>
<td>Assess unique learning needs based on the individual’s needs and beliefs</td>
</tr>
<tr>
<td>Set goals</td>
<td>Teach the individual to set wellness goals meaningful to him or her</td>
</tr>
<tr>
<td>Develop nursing care plan</td>
<td>Individual develops plan of action with the nurse and takes responsibility for carrying out the plan themselves</td>
</tr>
<tr>
<td>Carry out nursing interventions</td>
<td>Teach the person with MS how to effectively manage their own health</td>
</tr>
<tr>
<td>Evaluate results</td>
<td>Teach the individual to self-evaluate results</td>
</tr>
</tbody>
</table>

5.4 CARE MODELS IN MS

‘Comprehensive care in MS is an organised system of healthcare designed to address the medical, vocational, emotional, and educational needs of patients and their families’ (Halper & Holland, 2011).

Comprehensive care models emphasise a wellness approach in which the individual takes an active role in planning and implementing healthcare and self-care activities; the individual also acts as a consultant to the multidisciplinary care team, which may consist of a neurologist, nurse, occupational therapist, physiotherapist, psychologist, social worker, counsellor, dietician, speech and language therapist, continence advisor, general practitioner, etc. (Halper et al, 1994; Halper et al, 1997; Halper & Holland, 2011).

The individual with MS must learn to adapt and change in response to alterations in their physical functioning. Therefore, the individual and the multidisciplinary healthcare team must be committed to a clearly defined wellness programme that looks beyond the illness to each person’s full potential (Brechin et al, 2001; Cobble et al, 1985; Halper et al, 1997).

Providing dynamic care in MS often requires care plans – also called clinical pathways, or multidisciplinary action plans. Care plans outline the optimal sequencing and timing of interventions and include desired individual outcomes, timelines, collaboration, and comprehensive aspects of care (Halper et al, 1997; Ignatavicius et al, 1995).
5.4.1 The multidisciplinary team

In practice the MS nurse often acts as coordinator and point of contact for other members of the multidisciplinary team, organising meetings with all team members and involving the patient if appropriate, and/or acting as patient advocate. For multidisciplinary naïve patients the nurse often makes the initial necessary referrals. However, access to services and members of the multidisciplinary team can vary in different hospitals.

In addition to the neurologist, the MS nurse, and the GP, the multidisciplinary healthcare team involved in the care of individuals with MS may include (Halper et al, 1997; Halper & Holland, 2011):

- Physiotherapist
- Occupational therapist
- Social worker
- Psychologist and/or counsellor
- Continence advisor
- Dietician
- Speech and language therapist.

5.4.1.1 Physiotherapist

The physiotherapist assists the person with MS in improving or maintaining physical functioning through exercise. For example, gentle, sustained stretching exercises are beneficial in the management of spasticity. Consideration needs to be given to the temperature of the environment in which the physiotherapy takes place, as a cooler environment will reduce the risk of elevating body temperature, which leads to fatigue (Halper et al, 1997).

5.4.1.2 Occupational therapist

The occupational therapist focuses more specifically on functioning with respect to activities of daily living. They also advise/provide aids and adaptations to enable the individual to maintain their maximum level of independence and health. For example, for an individual experiencing fatigue, the occupational therapist may assess how the person with MS plans daily activities and will provide recommendations on how to minimise fatigue and/or perform activities during times when energy levels are higher. The occupational therapist may also recommend weighted eating utensils and cups to decrease tremor during eating (Halper et al, 1997).

5.4.1.3 Social worker

The social worker assesses the individual and their family’s overall living situation and assists in such areas as financial arrangements and benefit entitlements, community resources and care packages, employment issues and alternative living situations (Halper et al, 1997).
5.4.1.4 Psychologist

The psychologist can also help the person with MS and their family psychologically prepare for active participation in rehabilitation. The psychologist may assess psychological status, coping styles, problem-solving skills, and cognitive function. Through counselling, the psychologist assists the individual in developing or strengthening the tools needed to cope during periods of extreme stress or turmoil (Halper et al, 1997).

5.4.1.5 Continence advisor

The continence advisor works with the person with MS who has bladder or bowel problems to assess, plan and implement a care plan designed to meet the individual’s needs.

5.4.1.6 Speech therapist

The speech therapist evaluates and treats individuals with speech and swallowing difficulties. Ideally, speech therapy is initiated when the symptoms first appear and focuses on teaching and training techniques that compensate for reduced neuromuscular function, such as an exaggeration in articulation (Halper et al, 1997).

5.4.1.7 Public Health Nurse

The Public Health Nurse (PHN) is involved in health promotion, assessment of needs and coordinating care of the person with MS. The PHN may recommend a home help or a care assistant where appropriate and if feasible. PHNs work closely with the person with MS and help them to adapt to problems associated with daily living as a result of MS. The PHN liaises with the General Practitioner and Neurology team.

5.4.1.8 Dietician

The dietician provides a therapeutic and nutritional advisory service to improve a person's health. The dietician works as part of a multidisciplinary team in the care of those with MS in the hospital or people with MS (PWMS) may be referred as outpatients.

A case review of an MS patient’s care revealed the benefit of synergy between the interventions of two disciplines. The ongoing rehabilitation training of the physiotherapist complimented the work of the continence Clinical Nurse Specialist (CNSp) and led to a long term improvement in bladder problems and in quality of life, as measured using the King’s Health Questionnaire (Hay-Smith et al, 2011).

A Swedish study, which aimed to evaluate the effects of neurorehabilitation in MS patients found improvements in health related quality of life after a 3 week multidisciplinary rehabilitation programme. The therapists involved were from the following disciplines: physiotherapy, occupational therapy, speech therapy, psychology and social work (Vikman et al, 2008).
5.4.2 References

Bates D, Fieschi C, Lucas K et al. Clinicians and people with MS: views on MS and its management. Presentation made at the European Committee for Treatment and Research in Multiple Sclerosis Fourth Annual Meeting of America’s Committee for Treatment and Research in Multiple Sclerosis; Sept 15–18, 1999; Basel, Switzerland. Presentation made at the MS Forum’s Fifth Interactive Symposium; Sept 16, 1999.


5.5 NURSING ASSESSMENT

5.5.1 Introduction

MS can affect the individual’s parental, relationship, vocational, and social roles and can significantly impair peoples’ quality of life. Therefore, in addition to the assessment of physical aspects of the disease, the assessment of psychosocial issues is an integral component in the comprehensive care and management of individuals with MS. The MS nurse specialist has a key role in aiding patients to adjust to their condition through expert assessment, guidance, support and education (Corry et al, 2011). This can be achieved by establishing a trusting relationship and then bringing the patient and family/carers to an understanding of the sequence or pattern of symptoms, therapy and rehabilitation programmes and their (the patient’s, family/carer’s) perceptions and reactions to them.

Ideally, newly diagnosed individuals will be seen by the MS nurse for an initial consultation on each visit to the clinic (Burgess, 2002). During the initial visit, the nurse should undertake a comprehensive holistic assessment. At each subsequent visit a review of information collected during previous visits is undertaken. Where indicated, if during the visit, the nurse believes that the clinical or functional status of a particular individual is impaired, a more detailed assessment should be undertaken to determine the effect of MS on the individual’s mobility, ability to engage in work, mood level, social interaction, the need for any aids or adaptations, and the availability of personal support. A referral to the appropriate rehabilitation or vocational service is made once both the perceived and actual needs of the individual are determined and the purpose of the service as well as process involved in participating in this service is discussed in detail with the individual (LaRocca & Kalb, 1997).

When collected in a systematic way, the information elicited during the assessment interview can be used to identify relevant psychosocial issues faced by PWMS (O’Connor & Eggert, 1994). In addition, this information may serve as a framework for assessment and management by referral sources and other healthcare professionals involved in the care of PWMS.

In this section, the goals and objectives of the initial nursing interview are discussed and nursing assessment strategies are described.

5.5.2 Learning objectives

After completing this section, the reader will be able to:

- Discuss the goals and objectives of the initial nursing interview
- Describe and apply nursing assessment strategies.
5.5.3 Goals and objectives of the nursing interview

The nurse can ask the individual what symptoms/issues are of most concern to him or her as these may differ from those the nurse and/or doctor believe are of most concern. Corry et al (2011) suggest that the MS patient can often comfortably discuss issues with the MS nurse that they would not discuss with others. It is important to establish if there is comprehension around what can and cannot be done in relation to the disease.

The objectives of the nursing interview are:

- To establish the individual’s perceptions and expectations relating to MS and their expectations of what can be achieved
- Identify the physical, emotional, spiritual, and educational needs of the individual
- Encourage the patient and family to verbalise concerns about levels of functioning
- Assist the individual and their family in coping with actual or potential changes in daily living resulting from MS
- Formulate a plan for individual care and management
- Refer individual to appropriate members of the multidisciplinary healthcare team
- Provide educational literature and information on support services
- Provide a mechanism for longitudinal follow-up and evaluation.

5.5.4 Assessment

- Undertake a comprehensive physical assessment to identify specific symptoms patient is experiencing; please see Chapter 4
- Determine the symptoms and/or issues that are of most concern to the individual
- Assess how the individual, family, and/or primary caregiver are coping with the physical and functional disabilities associated with MS through assessment of coping behaviours
- Assess whether the following factors may influence coping strategies:
  - Support provided by family, friends and significant others
  - Other stressors not necessarily related directly to the MS
  - Educational needs
  - Previous experience with health problems
  - Spirituality
  - Alterations in social/leisure activities
  - Employment issues
Assess how the individual is coping with the diagnosis and identify what crisis stage the individual is currently in (see Figure 5.1); adjust counselling strategies and interventions accordingly

- Perception of event (i.e. does individual feel this is a crisis situation?)
- Preservation of emotional balance and self-image
- Maintenance of significant relationships
- Preparedness for an unpredictable future

Assess the individual’s level of dependence on others

Assess type of coping skills:
- Problem-focused
  - Seeks information
  - Establishes goals
  - Rehearses alternatives
- Emotion-focused
  - Denies or minimises problems
  - Requests reassurance or support
  - Finds a general purpose or meaning in life

Assess for the following non-pharmacological health-maintenance behaviours:
- Exercise
- Proper diet
- Use of stress-reduction techniques
- Adequate rest/sleep
- Use of alternative therapies

Assess whether any of the following issues need to be immediately addressed:
- Employment
- Disability
- Financial
- Child care

Identify therapy options and make appropriate referrals.
5.5.5 Cullberg’s crisis theory (1992)

A good knowledge and understanding of Cullberg’s crisis theory (1992) will help the nurse to understand how patients are likely to react on receiving the diagnosis. The stages of Cullberg’s crisis theory are presented in Figure 5.1.

Figure 5.1. Cullberg’s crisis theory (1992).

5.5.5.1 Shock stage

According to Cullberg’s theory, the shock stage is of short duration and immediately follows the crisis. The patient is experiencing extreme confusion and inner turmoil but appears calm on the surface. Afterward, the patient may have difficulty remembering what happened after the shock phase. For example, the patient may claim that he/she was told of the diagnosis in a very hurried and unsympathetic manner with little, if any, explanation about the disease. During this phase, the nurse should build a strong nurse-patient relationship and ensure that the patient receives initial information about the disease. The nurse should also ensure that information and advice given during this stage are repeated later.
**5.5.5.2 Reaction stage**

During the reaction stage, the patient can no longer shut out the painful truth about the disease and may begin to express strong emotions. The reaction stage may last from a few months to a year. During this stage, the patient may resort to many primitive defence strategies such as denial, projection, and regression. Sometimes a patient may remain in the reaction stage for years, seeking help from miracle cures and alternative medicines. As the reaction phase progresses, the MS patient becomes ready to participate in educational programs or activities that will help him/her gather resources that are vital for rehabilitation.

**5.5.5.3 Restoration stage**

During this phase, the patient begins to look to the future rather than live in the past, as in the previous stages. The patient begins to actively seek information and guidance. Further education can be given at this stage and the guidance provided during the shock stage can be repeated now.

**5.5.5.4 Re-orientation stage**

The re-orientation stage is a life-long phase. The person learns to live with the disease and the limitations relating to it. He/she learns to accept help when it is needed, but also learns the importance of his/her own initiative. Patients do not always necessarily reach this stage. The typical symptoms of failing to reach this stage include low self-esteem, bitterness, and a tendency to isolate oneself from social contacts.

**5.5.6 References**


**5.5.7 Suggested reading**


5.6 CARE PLAN FOR NEWLY DIAGNOSED INDIVIDUALS

5.6.1 Introduction

Nurses play a critical role in the education and support of newly diagnosed individuals and their families. They play a key role in the provision of information and education (Shaw & McMillian, 2008; cited Corry et al., 2011). This role demands that nurses have a comprehensive understanding of the disease process and the effects of MS on overall individual health and life status. The physiological, social and behavioural responses of the person to the illness are integral components of nursing care.

A diagnosis of MS can evoke an array of emotional responses that range from shock, grief, anger, and fear, to profound relief in the knowledge that the reason for symptoms has finally been discovered. Therefore, nurses should develop care plans that effectively ease individuals’ movement through this emotional roller coaster and assist in the development of an effective nurse-individual relationship (McGuiness et al., 1999; Van Manen, 1998).

In this section, a care plan for newly diagnosed individuals is presented (see Table 5.2).

5.6.2 Learning objective

After completing this section, the reader will be able to:

- Develop a care plan for newly diagnosed MS individuals.

<table>
<thead>
<tr>
<th>NURSING DIAGNOSIS</th>
<th>INTERVENTION</th>
<th>RATIONALE</th>
<th>DESIRED INDIVIDUAL OUTCOME(S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety relating to knowledge deficit of disease process</td>
<td>Review individual’s present knowledge and understanding of MS in general and the available treatments. Expand individual’s present knowledge base.</td>
<td>Basic knowledge may already be present. Individual may have misconceptions about the disease.</td>
<td>Understands disease process</td>
</tr>
<tr>
<td>Uncertainty about future physical and social capabilities</td>
<td>Provide positive information. Provide educational material. Expand individual’s present knowledge base.</td>
<td>Positive information allows the individual to remain hopeful throughout the disease process.</td>
<td>Confident about the future</td>
</tr>
<tr>
<td>NURSING DIAGNOSIS</td>
<td>INTERVENTION</td>
<td>RATIONALE</td>
<td>DESIRED INDIVIDUAL OUTCOME(S)</td>
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<td>----------------------------------------------</td>
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<tr>
<td>Worries regarding parenting</td>
<td>• Provide relevant information about pregnancy and parenting issues in relation to MS</td>
<td>• Given all relevant information, parenting should be an individual decision</td>
<td>• Understands issues related to MS and parenting</td>
</tr>
<tr>
<td>Inability to recognise the symptoms of an attack</td>
<td>• Provide information about what constitutes a true attack</td>
<td>• Knowledge of symptoms of true and pseudo attacks reduces anxiety</td>
<td>• Distinguishes between the symptoms of a true MS attack and those of a pseudo attack</td>
</tr>
<tr>
<td>Nonadherence relating to denial of diagnosis</td>
<td>• Review diagnostic criteria and classification</td>
<td>• Individual may be confused about the certainty of the diagnosis</td>
<td>• Accepts diagnosis</td>
</tr>
<tr>
<td>Powerlessness relating to unpredictable nature of disease</td>
<td>• Review individual’s comprehension of his/her prognosis</td>
<td>• Individual may have preconceived ideas and misconceptions about future abilities</td>
<td>• Possesses realistic expectations of disease process and future abilities</td>
</tr>
<tr>
<td>Grief relating to loss of former self</td>
<td>• Reinforce that grieving is acceptable</td>
<td>• Grieving allows the individual to move forward</td>
<td>• Accepts disease</td>
</tr>
<tr>
<td>Confusion relating to difficulty in distinguishing which symptoms are related to MS and which are related to other conditions</td>
<td>• Educate the individual about the disease process and other conditions that may coexist with MS</td>
<td>• Wellness and an understanding of the disease process promote a healthy outlook on life</td>
<td>• Recognises that other conditions may be responsible for symptoms</td>
</tr>
<tr>
<td>Information-seeking relating to:</td>
<td>• Direct individual to appropriate information resources (e.g. library, literature packages supplied by clinics, MS society, MS Trust, reputable websites and other appropriate local resources)</td>
<td>• Empowerment is gained through knowledge</td>
<td>• Possesses correct knowledge of disease</td>
</tr>
<tr>
<td>• Need to confirm present knowledge</td>
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<tr>
<td>• Need to make informed decisions about available treatment options, resources, and supports</td>
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<tr>
<td>• Need for control</td>
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</table>
Note: The plan for educational sessions with newly diagnosed individuals should include discussions on how the diagnosis is made and the definitiveness of the diagnosis. The individual should be encouraged to guide the course of the session. In order to promote individual understanding, the function and purpose of paraclinical tests should be reinforced.

5.6.3 References


5.6.4 Suggested reading

5.7 SEXUALITY, FAMILY ISSUES AND PREGNANCY

5.7.1 Introduction

The private and intimate nature of issues surrounding sexuality makes it difficult for both individuals and healthcare professionals to discuss these issues. 80% of MS patients experience sexual dysfunction (Demirkiran et al., 2006; cited in Katz, 2011). Individuals may be unaware that sexual problems can be related to MS and may be embarrassed to share their concerns, believing that nurses or other healthcare professionals will somehow think less of them. However, if an individual’s concerns about their sexuality go unattended following the initial diagnosis, it becomes more likely that they will never be addressed as the disease progresses. Therefore, MS management should always include an assessment of an individual’s sexual functioning from initial diagnosis onward (Halper et al., 1997; SHSBCRS 1997–1998; SOGC, 1987; Taylor et al., 1987). It is also important to note that sexual dysfunction affects women as well as men.

Family issues are also often overlooked during the nursing assessment as individuals may find it difficult to discuss these issues. However, in order to achieve a full understanding of the burden of illness and implement appropriate interventions, it is important for nurses to determine the impact of MS on individuals’ families. Burgess (2010) suggests that the needs of the patients’ partners and family members are often overlooked at diagnosis where feelings of anger, loss of control and social isolation have been reported.

Because MS is frequently diagnosed in women of childbearing age, nurses will often find themselves involved with pregnancy issues. Nurses play an important role not only in answering individual’s questions about pregnancy and how to cope as a mother with a disability, but also in ensuring that these women are given evidenced-based and up-to-date information concerning this specific area of care.

In this section, strategies for assessing sexual and family issues are discussed. Care plans for the management of difficulties in these areas are also presented. Information on pregnancy and MS is provided in a question and answer format.

5.7.2 Learning objectives

After completing this section, the reader will be able to:

- Describe and apply strategies for the assessment of sexuality and family issues
- Develop and apply care plans for difficulties related to sexuality and the family
- Answer individual’s questions about MS and pregnancy.
5.7.3 Sexuality

5.7.3.1 Assessing sexuality

- Assess own knowledge of human sexuality and evaluate personal attitudes, values, and beliefs towards sex and sexuality (as nurse’s own comfort level with sexuality will have a significant effect on the efficacy of interventions)
- Assess the following:
  - History of the specific sexual problem
  - Perceptions of how MS has affected sexual functioning
  - Gender(s) of sexual partner(s)
  - Significance of sexual relationship to the individual/spouse/significant other
  - Usual pattern of sexual activity
  - Attitude toward modifying usual sexual pattern
  - Knowledge of available treatment options
- Assess sexual health using the Sexual Health Assessment Framework (see Table 5.3)
- Apply the PLISSIT model (see Figure 5.2) to guide nursing interventions (this model provides a systematic way of addressing sexual health concerns)
- Provide the individual with preliminary education based upon the outcome of both the PLISSIT model and the sexual-health assessment and refer individual to the appropriate professional when specific suggestions and interventions are required that are beyond the nurse’s level of expertise
- Follow care plan for individuals who have difficulty discussing sexual issues and needs (see Table 5.4).

Note: Remember that MS is not always the cause of psychosocial problems/difficulties.

When dealing with sexual issues, the PLISSIT model can assist nurses in deciding the level of intervention needed for a particular individual. PLISSIT is an acronym for permission, limited information, specific suggestions, and intensive therapy. These components of the acronym form the levels of the pyramid shown in Figure 5.2. Permission, at the base of the pyramid, applies to the majority of individuals, while intensive therapy, at the top of the pyramid, applies to relatively few individuals (McBride & Rines, 2000). Each of these levels is described in detail in Figure 5.2.
Table 5.3. Sexual Assessment Framework. Adapted from Szasz (1989). This framework can assist nurses in identifying individuals’ sexual concerns and can also be used to guide nursing assessments and interventions for managing changes to sexuality resulting from MS (Breen & Rines 1996; Eckland & McBride, 1997; McBride & Rines 2000; Szasz, 1989).

<table>
<thead>
<tr>
<th>ASSESSMENT</th>
<th>DESCRIPTION</th>
</tr>
</thead>
</table>
| Sexual knowledge      | - Determine the individual’s understanding of changes to sexuality that result from MS  
- Determine the individual’s values and beliefs about sex and sexuality  
- Do not make any assumptions regarding the individual’s knowledge or values; always clarify the individual’s perceptions of the impact of MS on sexual function and sexuality |
| Sexual self-view      | - Determine the individual’s sexual self-view (i.e. individuals with MS may remain sexual but may be challenged to define their sexual self-view; for example, prior to requiring a wheelchair, individuals may view persons in wheelchairs as not being sexual; this belief will influence how individuals may view themselves if they require a wheelchair) |
| Sexual activity       | - Determine the individual’s ability to engage in sexual activity by assessing motor abilities, balance, strength, and bowel and bladder function  
- Determine whether activities such as dressing and undressing, transferring, and affectionate activities, such as hugging and petting, need to be re-examined  
- Instruct the individual on new positions and techniques; instruction will need to be individualised according to individuals’ comfort level, interests, and physical abilities; this function may require referral to a specialist in sexual health |
| Sexual response       | - Determine the individual’s sexual response  
- Sexual response in women refers to general physiological changes (e.g. increased heart rate and blood pressure, skin flush) as well as genital vasodilatation, vaginal lubrication, nipple erection, and orgasm (Breen & Rines, 1996)  
- Sexual response in men includes general physiological changes (as above), penile erection, testicular elevation, pre-ejaculation, ejaculation, and orgasm  
- Changes to sexual response will vary greatly from individual to individual and are dependent upon the level of disability |
| Sexual interest and behaviour | - Determine the individual’s ability to initiate or maintain social/sexual relationships; maintaining such relationships is a fundamental concern for most individuals  
- More detailed assessments of the individual’s values and beliefs, social and communication skills, and sexual history may be needed  
- Assess whether the individual’s partner has assumed any care-giving activities that may threaten the individual’s role as a lover |
1. **Permission**
   As the foundation of the pyramid, permission is the most important level because it provides an opportunity for individuals and/or their partners to begin discussing their sexual concerns. Permission includes verbally acknowledging individuals’ concerns about their sexuality and telling them that these concerns are normal.

2. **Limited Information**
   At this level of the pyramid, individuals are asked to discuss their concerns in more detail and are also offered some general information aimed at dispelling myths about sexuality and disabilities.

3. **Specific Suggestions**
   At this level, individuals and/or their partners receive specific information in response to their questions and concerns about sexuality. Although this level of intervention requires a broader knowledge base than is needed for the limited information level, nurses can successfully intervene at this level by applying their knowledge of MS to individuals’ situations. For example, the nurse may give a particular individual suggestions on how to manage spasticity during sexual activity based on information about what triggers and relieves spasms.

4. **Intensive Therapy**
   This level of intervention requires specialised knowledge and training in the area of sexuality and MS (such as a psychosexual counsellor). Therefore, it may be necessary to refer the individual to a healthcare professional that is more qualified to implement intensive therapy (Eckland and McBride 1997). However, nurses whose area of expertise is sexuality and MS may be able to respond to individuals’ concerns at this level.
The level of intervention used will vary from individual to individual and will also vary depending on the nurse’s comfort level, sexual knowledge, values, and beliefs. If the nurse is not competent in dealing with this issue, the patient must be referred on as appropriate.

Table 5.4. Care plan for individuals who have difficulty discussing sexual issues and needs.

<table>
<thead>
<tr>
<th>INTERVENTION</th>
<th>RATIONALE</th>
<th>EXPECTED INDIVIDUAL OUTCOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide an open, non-judgmental atmosphere for discussion</td>
<td>Facilitates open expression of feelings about perceived changes in sexuality</td>
<td>Effectively communicates sexual concerns and needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Expresses actual or perceived limitations imposed by MS and openly verbalises feelings regarding changes in sexual identity</td>
</tr>
<tr>
<td>Ensure privacy</td>
<td>Conveys respect for the individual and the sensitive nature of the individual’s concerns</td>
<td>Effectively communicates sexual concerns and needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Expresses actual or perceived limitations imposed by MS and openly verbalises feelings regarding changes in sexual identity</td>
</tr>
<tr>
<td>Ask the individual’s permission before moving on to an area of assessment (e.g. “Is it okay if I ask you some questions about the sexual part of your life?” Later on in the interview ask, “May I ask about what changes you’ve experienced in body sensations?”)</td>
<td>Conveys respect for the individual and the sensitive nature of the individual’s concerns</td>
<td>Effectively communicates sexual concerns and needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Expresses actual or perceived limitations imposed by MS and openly verbalises feelings regarding changes in sexual identity</td>
</tr>
<tr>
<td>Begin with general questions and then move to more specific questions</td>
<td>Conversation should progress from the least sensitive areas to most sensitive areas (e.g. ask about changes in bladder and bowel function before asking about changes in sexual function) (McBride &amp; Rines, 2000)</td>
<td>Effectively communicates sexual concerns and needs</td>
</tr>
<tr>
<td>INTERVENTION</td>
<td>RATIONALE</td>
<td>EXPECTED INDIVIDUAL OUTCOME</td>
</tr>
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<td>-------------</td>
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</tr>
</tbody>
</table>
| Normalise and validate the individual’s concerns (e.g. say, “Many people feel this way” or “Women often ask that question.”) | • Ensures that the individual does not feel alone or unusual for having sexual concerns | • Demonstrates an improved self-perception of desirability and self-image  
• Explores alternate sexual behaviours/patterns |
| Provide reassurance based on facts | • Kind words that are not based on factual information may instill false hope in the individual (McBride & Rines, 2000) | • Demonstrates an improved understanding of the limitations imposed by MS |
| Use neutral language | • Allows individual to express concerns without fear of being judged  
• Neutral words such as “partner” facilitate a more open discussion of sexual concerns – regardless of sexual orientation – than words such as “husband” or “wife”  
• Neutral phrases such as “changes in erections” have less of a negative impact on individuals’ self-esteem than words such as “impotence” | • Demonstrates an increased understanding of the limitations imposed by MS  
• Expresses a willingness to seek more expert assessment and treatment  
• Demonstrates an improved level of knowledge of available options |
5.7.4 Family issues

5.7.4.1 Assessing family issues

The CNSp may involve the social worker at this point in the assessment of social and financial issues.

- Assess family coping behaviors and problem-solving techniques
- Assess family support system
- Assess family activities and financial resources
- Assess assumed and/or perceived family roles and the impact MS has on these roles
- Assess the perceived impact of MS on the family’s assumed and expected roles
- Assess family interaction and communication patterns, including expressions of:
  - Anger
  - Fear
  - Despair
  - Affection
- Assess family members’ level of understanding and knowledge of MS
- Encourage the expression of feelings related to perceived or potential losses and determine the impact of these feelings on the family’s well-being
- Follow care plan for difficulties related to family issues (see example in Table 5.5).

**Note:** Remember that MS is not always the cause of psychosocial problems/difficulties.
### Table 5.5. Care plan for difficulties related to family issues (Amason et al, 1995; Aronson et al, 1996; Hartrick et al, 1995; Hyde et al, 1986; Paty et al, 1999; Taylor et al, 1987).

<table>
<thead>
<tr>
<th>NURSING DIAGNOSIS</th>
<th>UNDERLYING CAUSE</th>
<th>INTERVENTION</th>
</tr>
</thead>
</table>
| **Grief**         | Loss of “normal” family unit | · Encourage family to identify source of fear  
· Educate family on MS  
· Refer family to appropriate counsellor and to family and community support groups  
· Assist individual and family in understanding the grieving process  
· Ensure individual and family understand that feelings of grief are “normal” under the circumstances |
| **Anger**         | Diagnosis of a chronic illness | · Provide family and individual with outlets for expressing anger  
· Educate family and individual with respect to positive coping strategies |
| **Fear**          | Related to the uncertainty of future events | · Educate family on disease process |
| **Guilt**         | Disease pathogenesis or process itself | · Allow expression of guilt  
· Provide reassurance  
· Ensure individual and family understand that feelings of guilt are “normal” under the circumstances |
| **Denial**        | Refusal to acknowledge disease process | · Assess family's knowledge of the disease and disease process  
· Educate the family on the diagnosis and the disease process  
· Provide family with the opportunity to express their interpretation of the individual’s situation  
· Acknowledge denial as a reasonable response to a potentially devastating diagnosis  
· Support individual through the disease process |
<table>
<thead>
<tr>
<th>RATIONALE</th>
<th>EXPECTED INDIVIDUAL AND FAMILY OUTCOME(S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying the source of fear reduces the likelihood that the nurse will implement ineffective interventions by making false assumptions about the source of fear. Education and support help the family cope with MS.</td>
<td>Use supports to reduce fear. Communicate feelings of comfort and understanding. Develop or refine coping strategies that enable them to adapt to the demands of the illness without destroying family balance.</td>
</tr>
<tr>
<td>Recognition of anger leads to the development of more positive coping strategies.</td>
<td>Vent anger in a positive fashion.</td>
</tr>
<tr>
<td>Improved knowledge reduces fears.</td>
<td>Demonstrate an improved understanding of the disease process. Fear future events less.</td>
</tr>
<tr>
<td>Expression and alleviation of guilt help maintain healthy family dynamics.</td>
<td>Demonstrate an increased understanding of the disease process. Acknowledge that guilt is an allowable emotion. Understand that the individual acquiring the disease was no one’s fault.</td>
</tr>
<tr>
<td>Refusal may be due to lack of information. Understanding the family’s own interpretation of the individual’s situation reduces the possibility that the nurse will make erroneous assumptions when planning appropriate care. Acknowledging denial legitimises the family’s initial response as acceptable under the circumstances. Education and support improve the family’s understanding of MS and their response to the disease. Reinforces the family’s acceptance of individual responses to MS. Provides an opportunity to revisit the potential problematic responses to denial and promotes future acceptance of the disease.</td>
<td>Acknowledge disease. Increase level of trust in the nurse. Facilitate opportunity to revisit potential problematic response to denial and promote future acceptance of the disease.</td>
</tr>
</tbody>
</table>
5.7.5 Pregnancy and childcare

Because MS is frequently diagnosed in women of child-bearing age, nurses are often asked specific questions to do with both pregnancy and childcare. Nurses are in the perfect positions to provide education to patient regarding the realities of living with MS (Katz, 2011). Nurses play a vital role as an educator of patients and their families and the following is written in a question and answer format to assist nurses when discussing these particular issues.

**Will I pass MS on to my child?**

No. MS is not an inherited condition, although there is a slightly higher chance of your child developing the disease compared to the average population. The risk to a child with a parent who has MS is estimated at between 1 and 4%, but this is considered low and should not discourage you and your partner from having a family.

**Rationale:**

Although MS is not inherited, and in the majority of cases affects just one member of the family, approximately 20% of PWMS will have another family member with the condition (Sadovnick et al, 1993). In the general population the risk of MS is approximately 0.1%, but for a person whose sibling or parent has MS, this increases to a 2–4% chance of developing the disease.

This risk is considered low, and as the genes involved in MS have not been identified, there is no genetic test available. During the preconception period, the family incidence will obviously need to be discussed and the couple counselled accordingly.

**Will having a baby make my MS worse in the long term?**

No. There have been a variety of studies carried out in this particular area showing that pregnancy does not alter the long-term course of MS. Tsui & Lee et al (2011) state that pregnancy does not affect MS disease progression and several studies suggest pregnancy has a beneficial effect; see for example Runmarker et al (1995) and D’Hooghe et al (2010).

**Rationale:**

Prior to 1949 neurologists advised women with MS not to become pregnant because they would be unfit mothers, their MS would get worse, they would become more disabled, and they would pass the disease on to their child. There was no data to support or refute this practice, which was based more on anecdotal testimony than scientific evidence. It is now accepted that these beliefs are clinical myths. A landmark study was published in 1950 demonstrating there was no substantial evidence that pregnancy affected levels of disability, and advice given to women wanting to become pregnant began to change.

There is evidence that women will forego pregnancy once a diagnosis of MS is made (Damek & Shuster, 1997), even though it is now established that the long-term course of MS is unaffected by pregnancy (Confavreux et al, 1998; Rouillet, et al 1993; Thompson et al, 1986). There have been numerous reputable studies published examining the effect of MS on pregnancy and in particular the incidence of relapses. Most of these studies have focused on women who have a mild form of relapsing remitting disease and, are generally able to care for themselves and as a consequence, these results cannot be generalised to women with more progressive disease.
Will MS affect my fertility?

No. It is well established that MS does not affect fertility, conception or gestation, nor does it affect the chances of a baby being born with abnormalities. There is no evidence that MS causes an increase in ectopic pregnancies or has any effect on your chances of miscarriage or premature birth. The birth weight of your baby will be unaffected.

Rationale:

Infertility is no more common in women with MS than the general population (Confavreux et al, 1998). This particular study also demonstrated that MS does not have any adverse effects on the either the pregnancy, the delivery or the unborn child (other than the familial link as previously mentioned).

Although the disease does not have any direct effect on fertility, the frequency of childlessness is significantly greater in PWMS than the general population (Runmarker & Andersen, 1993) and it is commonly accepted that women severely disabled by MS choose not to become pregnant.

The other issue to consider is that sexual dysfunction is common in women with MS and again, whilst this does not affect biological fertility, it is known that MS can reduce sexual libido and orgasmic capacity (Hulter & Lundberg, 1995), which may have an impact on sexual relationships and hence chances of conception.

Am I likely to have a relapse during my pregnancy?

Relapse rates are often affected during pregnancy and the first few months after delivery. Your risk of relapse during early pregnancy will probably not alter, but you are at a lower risk of relapse during the later months of pregnancy. However, you should be aware that the chance of having a relapse in the first few months after the birth is high. Once your baby is 6 months old, your relapse rate will have returned to its pre-pregnancy rate. Overall, the number of relapses you experience in the 12 month period of your pregnancy, and the immediate time after, is considered to be the same as the 12 months prior to your pregnancy.

Rationale:

In 1984 an Israeli study (Kom-Lubetz et al) was one of the first to demonstrate that relapse rate in the third trimester of pregnancy was significantly reduced, although there was a significant increase in relapses in the first 3 months post-partum. Other studies published since have supported this finding (Birk et al, 1990; Confavreux et al, 1998; Rouillet et al, 1993; Vukusic et al, 2004). Women are therefore advised that there is a trend towards lower relapse rate during the third trimester of pregnancy but they face an increased risk of experiencing a relapse during the post-partum period. Confavreux et al (1998) also demonstrated that disease activity, as shown by magnetic resonance imaging (MRI), was reduced particularly during the third trimester, but does increase again in the first 3 months post-partum (Bashir & Whitaker, 2002). However, because the relapse rates decline during the 9 months of pregnancy, but then generally increase in the first 3 months post-partum, the overall effect of pregnancy on MS is considered neutral.

These changes are thought to be due to the relationship between the endocrine and immune systems. It is believed that oestrogen inhibits T-cell mediated diseases such as MS by altering T-cell activation, reducing the production of pro-inflammatory cytokines, and interfering with maturation of macrophages (Houtchens et al, 2000). These changes explain why the relapse rate decreases late in pregnancy, when oestrogen production is high, and also the two to three fold increase in relapse rate post-delivery when oestrogen levels plummet (Confavreux et al, 1998).
In one study (Achiron, 1996), women who had previously experienced childbirth associated relapses were given prophylactic treatment with intravenous gamma globulin. This treatment was found to significantly reduce their risk of relapse post-partum in a subsequent pregnancy. A follow up study by Achiron et al (2004) suggests that intravenous immunoglobulin treatment in relapsing remitting multiple sclerosis (RRMS) reduces relapse rate during pregnancy and in the postpartum period.

**Will pregnancy make my current symptoms worse?**

Most women with MS feel well during the pregnancy and the majority will complete it with no new problems. However, for a few women there is a possibility that some symptoms they already experience, such as fatigue and bladder problems, may increase. However, this is individual and any changes or increase in symptoms should be discussed with either your midwife, MS nurse, obstetrician or GP.

**Rationale:**

Although women with MS are generally well during pregnancy, some symptoms may be exacerbated, and may be difficult to distinguish from pregnancy symptoms (Smeltzer, 1994). Women should be warned of these possibilities when contemplating a pregnancy. Fatigue is extremely common in MS, and frequently occurs in early pregnancy in healthy individuals. It is therefore to be expected that fatigue will be exacerbated in women with MS, particularly in the first trimester. Bladder symptoms, e.g. frequency and urgency, may increase because of pressure on the bladder from the gravid uterus. Similarly, in late pregnancy, mobility problems can worsen, due to the increasing weight of the foetus and changes to posture.

**What about the medication I am on at the moment?**

This should be discussed with your GP or neurologist. As some medications are harmful to the baby during pregnancy, you may be advised to come off them, or have an alternative treatment prescribed before you become pregnant.

Many of the medications used to treat MS symptoms are contraindicated during pregnancy, e.g. amitriptyline, carbemazepine, oxybutynin, and women require accurate advice on withdrawing certain treatments and hence managing their symptoms or disease prior to conception.

**Can I receive steroids if I have a relapse during pregnancy?**

Steroids are best avoided in pregnancy where possible, but under certain exceptional circumstances (e.g. severe relapse) your neurologist may decide that the benefits outweigh the small risks. As steroids are known only to hasten recovery from relapses, and do not influence outcome, it is rarely essential that they are used in MS (see Case Study 1).
Pregnancy and breast-feeding

Following a review of the data on the safety of systemic corticosteroids used in pregnancy and breast-feeding the CSM (May 1998) has concluded:

- Corticosteroids vary in their ability to cross the placenta; betamethasone and dexamethasone cross the placenta readily while 88% of prednisolone is inactivated as it crosses the placenta.
- There is no convincing evidence that systemic corticosteroids increase the incidence of congenital abnormalities, such as cleft palate or lip.
- When administration is prolonged or repeated during pregnancy, systemic corticosteroids increase the risk of intra-uterine growth restriction; there is no evidence of intra-uterine growth restriction following short-term treatment (e.g. prophylactic treatment for neonatal respiratory distress syndrome).
- Any adrenal suppression in the neonate following prenatal exposure usually resolves spontaneously after birth and is rarely clinically important.
- Prednisolone appears in small amounts in breast milk but maternal doses of up to 40 mg daily are unlikely to cause systemic effects in the infant; infants should be monitored for adrenal suppression if the mothers are taking a higher dose.

(BMJ Group and the Royal Pharmaceutical Society of Great Britain, 2011)

CASE STUDY 1

Jenny a 24-year-old lady is married to Joe. She was diagnosed with MS 12 months ago. At her diagnosis, she asked the consultant whether she could become pregnant. His reply was yes, but ‘sooner rather than later’.

Joe contacts you to say that Jenny is experiencing a major relapse and she is now 11 weeks pregnant. They are overjoyed at the pregnancy, but are now frightened and anxious about Jenny’s condition. She is currently a patient in a small district hospital unable to walk more than a few steps, she is ataxic and experiencing regular falls. She is unable to care for herself and is dependent on others for all activities of daily living. She is having problems swallowing food and drink and the speech therapist is due to see them to discuss the insertion of a nasogastric tube.

The situation is made worse by the fact that Jenny is slightly confused and keeps forgetting she is pregnant. Joe asks you whether Jenny should have a course of steroids to treat her relapse. This treatment has been offered to them, but Joe is anxious that there is a risk to the baby. Joe feels that he has to make the decision regarding steroids on behalf of Jenny, as she is not capable of deciding for herself.

After much discussion with relevant healthcare professionals, it was decided that Jenny should not receive steroids. Despite experiencing such a disabiling relapse, this medication would not alter, in the long term, the degree of her recovery.

It took 5 weeks before Jenny was discharged home, but she did make a good recovery. She is now 36 weeks pregnant and the rest of the pregnancy has been uneventful.
What about receiving steroids when I am breastfeeding?

Steroids can appear in small quantities in breastmilk, especially in the high doses used to treat relapses. It may therefore be advisable that you do not breastfeed whilst receiving a course of steroids. Some mothers will express extra milk prior to commencing the course of steroids, which can be kept in the fridge or freezer and be given to your baby while you are having treatment. You may want to discuss this with an appropriate healthcare professional, e.g. health visitor or MS CNSp.

I am taking a disease modifying drug but want to become pregnant what should I do?

You are advised to discontinue treatment approximately 3 months prior to having sex with the aim of conception. You can recommence it again after the baby is born, but neither of these drugs should be taken if you are going to breastfeed.

Rationale:

Interferon beta therapies are contraindicated in pregnancy (Irish Pharmaceutical and Healthcare Association, 1995, 1997, 1998, 2003, updated 2011). Women taking beta interferon are advised to discontinue the treatment approximately 3 months before they stop taking contraception. Neither of these drugs have been formally tested for their safety in either women wishing to become, or are already pregnant. Whilst there have been reported cases of women having normal pregnancies and healthy babies who continue on beta interferon and copaxone it is not recommended (Hutchinson, 1997). Women are also advised to avoid breastfeeding if taking these drugs (British Medical Association, Royal Pharmaceutical Society of Great Britain 2001; BMJ Group and the Royal Pharmaceutical Society of Great Britain 2011).

Will my MS affect either my labour and/or delivery?

Usually no. Even if you experience fatigue, the best advice is that whenever possible you should have a normal delivery and not opt for a caesarean section.

Rationale:

Women often express concerns about an instrumental delivery or caesarean section, but in reality, women with MS rarely need to be treated differently. Certain circumstances dictate careful consideration, e.g. fatigue is common in MS, and could potentially interfere with the second stage of labour, hindering active pushing. Although this is more likely if the first stage of labour is lengthy, it is no justification for shortening labour artificially (e.g. by augmenting with Syntocinon).

For some women, lower limb weakness or spasticity may mean that it is difficult to have an active labour, or to assume certain positions for delivery, e.g. squatting. This should be discussed by the midwife and obstetric physiotherapist in the antenatal period, and the use of equipment and alternative positions explored (see Case Study 2). There are no absolute contraindications for any of the usual pain relief options during labour, i.e. TENS, entonox, pethidine, epidural anaesthesia. However, there is the possibility of TENS machines exacerbating lower limb spasms in some women with MS. Although epidural anaesthesia has in the past been implicated as the cause of relapses, a case report and a study confirmed that there are no adverse effects on MS (Confavreux et al, 1998; Salvador et al, 1997).

Needless to say, it is of great benefit for women with MS to be cared for in labour by a midwife who knows them, and their physical limitations, well.
CASE STUDY 2
Sally, aged 28, has secondary progressive MS with weakness and stiffness in the lower limbs affecting her mobility. Prior to her first (planned) pregnancy she withdrew anti-spasmodic medication on medical advice, but suffered increased spasms.
Late in pregnancy she experienced spasms of the hip adductor muscles (on the inside of the thighs), which made abducting the legs difficult. Obviously, changing position during labour, and delivering the baby in the traditional semi-recumbent position would be hard.
Prior to delivery the midwife and obstetric physiotherapist worked with Sally to explore alternative delivery positions.
She eventually had a full-term normal delivery (without analgesia) in the left lateral position, with her husband supporting the right leg.

Will I pass MS on to my baby if I breastfeed and will it make my MS worse?
You cannot pass on MS through breast milk. Breastfeeding will have no negative effects on either yourself or your baby. In fact, one study suggested that breastfeeding may have a positive effect on the disease and MS activity may possibly slow down if you breastfeed; however this is still under investigation and, as yet, cannot be confirmed.

If you have problems with numbness or weakness in your arms or hands, you may find it is difficult to position the baby when you are breastfeeding and may need assistance. Again discuss any problems such as this with your midwife or MS nurse, who may be able to make suggestions. The other symptom that may affect your ability to breastfeed is fatigue. All new mothers face the prospect of fatigue and this will be more likely for a mother who has MS. Again, it is important that you discuss concerns such as these with the professionals who are caring for you. They will be able to offer you advice in an attempt to limit its effect on your day to day living.

Rationale:
Mothers should be reassured that there is no danger of transferring MS through breast milk. It has been established that breastfeeding does not have any adverse effects on disease course. Confavreux et al (1998) even noted that there was a trend towards less disease activity with breastfeeding. Unfortunately the numbers were too small to reach any statistical significance.

How will I cope once the baby is born?
If you have relapsing remitting disease you stand a higher risk of having a relapse in the first 3–6 months after the baby is born. The relapse may be more severe than those you normally experience (Worthington et al, 1994). This is important to consider when planning for the baby as you will need to arrange extra support from your family and friends during this time. By 6 months after the birth, your relapse rate should return to your pre-pregnancy rate (Confavreux, 1998; Worthington et al, 1994).
5.7.6 Summary

There is a wealth of evidence-based information, and invaluable support networks available for PWMS who aspire to start a family. Despite this, people continue to receive outdated or inaccurate advice, and are unaware of services or organisations that could benefit them. Consequently prospective parents with MS may feel unnecessarily isolated, lonely or anxious, or even relinquish having a family.

Providing care and information in this situation can be satisfying for the healthcare professional as the outcomes can be very positive. Healthcare professionals can do much to dispel myths and allay fears, thus empowering PWMS to approach pregnancy and parenthood well equipped and with confidence.

5.7.7 References


5.7.8 Suggested reading


5.8 FINANCIAL AND VOCATIONAL ISSUES

5.8.1 Introduction

Financial and vocational issues are not always thoroughly examined during medical visits as many healthcare professionals believe they can play only a limited role in addressing these issues. However, when collected in a systematic way, financial and vocational information can be used to identify and successfully manage psychosocial issues (O’Connor & Eggert, 1994).

5.8.2 Learning objectives

After completing this section, the reader will be able to:

- List tools for the assessment of financial and vocational issues
- Develop and apply care plans for financial and vocational difficulties.

In this section, assessment of vocational and financial difficulties is discussed and a care plan for managing these difficulties is presented.

Assessments of individuals’ financial and vocational status should include detailed evaluations of the following:

- Source of income
- Individual’s social support networks
- Nature of the individual’s current occupation
- Impact of MS on the individual’s ability to fulfill vocational roles
- Issues regarding transportation and accessibility
- Accommodations made by employers to create an accessible environment and modify the individual’s vocational duties
- Knowledge of resources that can assist the individual financially during relapse events.

Nurses should also be cognisant of: legislation and services that support the employment of persons with disabilities; Disability Rights Act; Disability Discrimination Act and government-linked financial support programmes available through disability living allowance, etc. In addition, nurses should inform individuals and their families that there may be local community/employee support programmes that may help address issues specific to their situations (Friehe et al, 1996; McLaughlin, 1998). To find out more about these, it is best to contact the Citizens Information Centre or the local branch of the MS Society. It may also be useful to search internet websites for local resources.
5.8.3 Benefits and entitlements for people with MS in Ireland

PWMS may be entitled to some of the following benefits. However, many of these are means tested. Please refer to the following webpage from The MS society of Ireland, where each of the available benefits are explained with links to specific websites (http://www.ms-society.ie/pages/benefits-and-entitlements-):

- Disability benefit
- Disability allowance
- Working and claiming a disability payment
- Disablement benefit and unemployed supplement
- Motorised transport grant – fully explained at the following link: www.hse.ie/eng/services/Find_a_Service/Iho/CavanMonaghan/Disability_Services/
- Mobility Allowance fully explained at the following link: www.hse.ie/eng/services/Find_a_Service/Iho/CavanMonaghan/Disability_Services/
- Exemptions/refunds for disabled drivers/passengers
- Disabled person's parking card
- East/West Link toll charges
- Reorganisation of services for people with disabilities
- Primary medical certificate – for severely disabled people, fully explained at the following link: www.hse.ie/eng/services/Find_a_Service/Iho/CavanMonaghan/Disability_Services/

**Carers:**

- Carers allowance
- Respite care grant
- Free travel
- Companion pass

**Benefits under EU Regulations and bilateral Social Security Agreements:**

- EU regulations
- Transferring UK disability benefits to Ireland
- Bilateral social security agreements
Health services:

- Medical card (www.hse.ie/eng/services/Find_a_Service/entitlements/Medical_Cards/)
- Long-term illness book (MS is listed as one of a long-term illness) now includes free GP cover (www.hse.ie/eng/services/Find_a_Service/entitlements/Long_Term_Illness/)
- Drug payment scheme (www.hse.ie/eng/services/Find_a_Service/entitlements/Drugs_Payment_Scheme/)
- Medical card Income guidelines
- VHI (www.vhi.ie/)
- Aviva (www.aviva.ie/online/health/)
- Laya Healthcare (www.layahealthcare.ie)
- Free travel to health services
- Prescribed drugs and medicines
- Dental, optical and aural services
- Aids and appliances
- Disability resource centre
- Long-stay nursing home
- Nursing home subvention

Community Care Services:

- MS Society (www.ms-society.ie/)
- Irish Wheelchair Association (www.iwa.ie/)
- PHN
- Home help
- Social workers
- Occupational therapies
- Physiotherapist
- Other community services
- Respite Care
- Personal Assistant Services
5.8.4 Citizens Information Centre

The Citizens Advice Centre provides free, confidential and impartial information on any subject to anyone who asks. There are over 80 centres around the country. Information is supplied on topics, such as income tax, health services, redundancy, housing, etc. (www.citizensinformation.ie/en/).

5.8.5 Suggested reading


5.8.6 Care plan

Implement care plan for anxiety/anger resulting from financial and/or vocational difficulties (see example in Table 5.6).

Table 5.6. Care plan for anxiety/anger resulting from financial and vocational difficulties (Burgess, 2002; Friehe et al, 1996; Gulick, 1991; Gulick, 1997; McLaughlin, 1998; O’Connor & Eggert, 1994).

<table>
<thead>
<tr>
<th>UNDERLYING CAUSE(S) OF ANXIETY/ANGER</th>
<th>INTERVENTION</th>
<th>RATIONALE</th>
<th>EXPECTED INDIVIDUAL OUTCOME(S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced social/financial status, earning potential, ability to work and/or inability to work at a regular job</td>
<td>· Identify individual limitations</td>
<td>· Allows nurse to verify individual's perceived limitations</td>
<td>· Expresses specific limitations in ability to perform vocational roles</td>
</tr>
<tr>
<td></td>
<td>· Direct individual to appropriate resources</td>
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<tr>
<td></td>
<td>· Refer individual to the appropriate rehabilitation or vocational services</td>
<td>· Helps the individual come to terms with the losses imposed by MS by providing a structure within which the individual's capabilities are assessed and matched to an appropriate activity or type of work</td>
<td>· Expresses a willingness to attend vocational assessment programmes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>· Attends referral to a rehabilitation/vocational service and participates in programmes structured to determine specific capabilities</td>
</tr>
<tr>
<td>UNDERLYING CAUSE(S) OF ANXIETY/ANGER</td>
<td>INTERVENTION</td>
<td>RATIONALE</td>
<td>EXPECTED INDIVIDUAL OUTCOME(S)</td>
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</table>
| Discrimination and prejudice in the workplace | · Provide individual with an opportunity to express feelings and describe events that were deemed discriminatory  
· Determine whether discrimination was an isolated event  
· Determine whether the discriminatory event was due to the behaviour of a single person (e.g. colleague or superior)  
· Determine whether services in the workplace exist that address the individual’s concerns and encourage the individual to make the appropriate report  
· Refer individual to a social worker or citizens advice bureau for further guidance  
· Direct individual to a local ombudsman/human rights centre  
· Inform individual of legislation and services supporting the employment of persons with disabilities | · Allows individual to express feelings about a discriminatory incident  
· Validates the individual’s right not to expect discriminatory treatment based on disability  
· Clarifies details of the discriminatory event  
· Social workers can implement strategies to help the individual cope with anger, anxiety, and frustration  
· Education about legal rights empowers the individual to secure these rights | · Aware of rights  
· Expresses satisfaction or a sense of achievement as demonstrated by avoidance of helpless behaviours and appropriate expression of anger |

| Financial difficulties | · Examine the individual’s financial needs and how well these needs are currently being met  
· Discuss the availability of alternate financial support (e.g. family, friends, benefits, occupational pension)  
· Inform individual of possible eligibility for financial assistance, e.g. income support or disability income  
· Refer individual to financial assistance services, e.g. CIC, Welfare Rights  
· Inform individual of Disability Rights Act | · Identification of the individual’s specific financial needs helps to develop realistic individual expectations about available resources  
· Knowledge of financial services and resources may help the individual achieve greater financial independence | · Identifies areas of financial need and available financial resources  
· Follows up on suggestions to contact social services, a social worker, and/or other appropriate community resources |
5.8.7 References


5.8.8 Suggested reading


Klaib RC. Multiple sclerosis: the questions you have. The answers you need. New York: Demos Publications; 1996.


5.9 PROGRESS CHECK

1. List five objectives of the nursing interview.
   a. ______________________________________________________________
   b. ______________________________________________________________
   c. ______________________________________________________________
   d. ______________________________________________________________
   e. ______________________________________________________________

2. List seven interventions for depression due to fatigue and/or pain.
   a. ______________________________________________________________
   b. ______________________________________________________________
   c. ______________________________________________________________
   d. ______________________________________________________________
   e. ______________________________________________________________
   f. ______________________________________________________________
   g. ______________________________________________________________

3. List three interventions for impaired memory.
   a. ______________________________________________________________
   b. ______________________________________________________________
   c. ______________________________________________________________
4. Complete the care plan for newly diagnosed individuals below.

<table>
<thead>
<tr>
<th>NURSING DIAGNOSIS</th>
<th>INTERVENTION</th>
<th>DESIRED INDIVIDUAL OUTCOME</th>
</tr>
</thead>
</table>
| Anxiety relating to knowledge deficit of disease process                         | - Review individual’s present knowledge and understanding of MS  
- Expand individual’s present knowledge base                                      |                            |
| Uncertainty about future physical and social capabilities                         | -                                                                                                                                                      | Confident about the future |
|                                                                                  | Provide relevant information about pregnancy and parenting issues in relation to MS  
-                                                                                                                                 | Understands issues related to MS and parenting |
| Inability to recognise the symptoms of an attack                                 | -                                                                                                                                                      | Distinguishes between the symptoms of a true MS attack and those of a pseudo attack |
| Nonadherence relating to denial of diagnosis                                      | -                                                                                                                                                      |                            |
| Powerlessness relating to unpredictable nature of disease                         | - Review individual’s comprehension of his/her prognosis  
-                                                                                                                                 |                            |
|                                                                                  | Reinforce that grieving is acceptable  
-                                                                                                                                 | Accepts disease |
| Confusion relating to difficulty in distinguishing which symptoms are related to MS and which are related to other conditions | -                                                                                                                                                      | Recognises that other conditions may be responsible for symptoms |
|                                                                                  | Direct individual to appropriate information resources  
-                                                                                                                                 |                            |
5. List seven interventions for individuals who have difficulty discussing sexual issues and needs.
   a. ______________________________________________________________
   b. ______________________________________________________________
   c. ______________________________________________________________
   d. ______________________________________________________________
   e. ______________________________________________________________
   f. ______________________________________________________________
   g. ______________________________________________________________

6. Complete the care plan for difficulties related to family issues below.

<table>
<thead>
<tr>
<th>NURSING DIAGNOSIS</th>
<th>UNDERLYING CAUSE</th>
<th>INTERVENTION</th>
<th>EXPECTED INDIVIDUAL AND FAMILY OUTCOMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grief</td>
<td>Loss of &quot;normal&quot; family unit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td>Diagnosis of a chronic illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear</td>
<td>Related to the uncertainty of future events</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guilt</td>
<td>Disease pathogenesis or process itself</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7. List five interventions for individuals with financial difficulties.
   a. ______________________________________________________________
   b. ______________________________________________________________
   c. ______________________________________________________________
   d. ______________________________________________________________
   e. ______________________________________________________________
5.10 PROGRESS CHECK ANSWERS

1. List five objectives of the nursing interview.
   a. Assist the individual and family in coping with actual or potential changes in daily living resulting from MS
   b. Identify the physical, emotional, spiritual, and educational needs of the individual
   c. Formulate a plan for individual care and management
   d. Refer individual to appropriate members of the multidisciplinary healthcare team
   e. Provide a mechanism for longitudinal follow-up and evaluation

2. List seven interventions for depression due to fatigue and/or pain.
   a. Assess for suicidal ideation
   b. Perform health assessment
   c. Assess sleep/rest patterns
   d. Perform pain assessment
   e. Involve partner/carer and/or family in interventions
   f. Inform GP of diagnosis
   g. Document all assessments and conversations with the individual

3. List three interventions for impaired memory.
   a. Provide written instructions as well as other memory aids such as lists, calendars, and daily activity logs
   b. Assist individual in reorganising work and home environments so that frequently used items are in familiar places
   c. Involve partner/carer and/or family in intervention.
4. Complete the care plan for newly diagnosed individuals below.

<table>
<thead>
<tr>
<th>NURSING DIAGNOSIS</th>
<th>INTERVENTION</th>
<th>DESIRED INDIVIDUAL OUTCOME</th>
</tr>
</thead>
</table>
| Anxiety relating to knowledge deficit of disease process    | · Review individual’s present knowledge and understanding of MS in general and the available treatments  
                               · Expand individual’s present knowledge base                                   | · Understands disease process                                                           |
| Uncertainty about future physical and social capabilities   | · Provide positive information                                              | · Confident about the future                                                               |
|                                                             | · Provide educational material                                               |                                                                                          |
|                                                             | · Expand individual’s present knowledge base                                 |                                                                                          |
| Worries regarding parenting                                 | · Provide relevant information about pregnancy and parenting issues in relation to MS | · Understands issues related to MS and parenting                                           |
| Inability to recognise the symptoms of an attack            | · Provide information about what constitutes a true attack                   | · Distinguishes between the symptoms of a true MS attack and those of a pseudo attack     |
| Nonadherence relating to denial of diagnosis                | · Review diagnostic criteria and classification                              | · Accepts diagnosis                                                                        |
| Powerlessness relating to unpredictable nature of disease    | · Review individual’s comprehension of his/her prognosis                     | · Possesses realistic expectations of disease process and future abilities                 |
| Grief relating to loss of former self                       | · Reinforce that grieving is acceptable                                       | · Accepts disease                                                                          |
| Confusion relating to difficulty in distinguishing which symptoms are related to MS and which are related to other conditions | · Educate the individual about the disease process and other conditions that may coexist with MS  
                               · Promote individual wellness                                                    | · Recognises that other conditions may be responsible for symptoms                   |
| Information-seeking relating to:                           | · Direct individual to appropriate information resources                     | · Possesses correct knowledge of disease                                                   |
| · Need to confirm present knowledge                         |                                                                            |                                                                                          |
| · Need to make informed decisions about available treatment options, resources, and supports |                                                                            |                                                                                          |
| · Need for control                                          |                                                                            |                                                                                          |
5. List seven interventions for individuals who have difficulty discussing sexual issues and needs.
   a. Provide an open, non-judgmental atmosphere for discussion
   b. Ensure privacy
   c. Ask the individual’s permission before moving on to an area of assessment
   d. Begin with general questions and then move to more specific questions
   e. Use neutral language
   f. Normalise and validate the individual’s concerns
   g. Provide reassurance based on facts

6. Complete the care plan for difficulties related to family issues below.

<table>
<thead>
<tr>
<th>NURSING DIAGNOSIS</th>
<th>UNDERLYING CAUSE</th>
<th>INTERVENTION</th>
<th>EXPECTED INDIVIDUAL AND FAMILY OUTCOMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grief</td>
<td>Loss of “normal” family unit</td>
<td>Encourage family to identify source of fear, Educate family on MS, Refer family to appropriate counsellor and to family and community support groups, Assist individual and family in understanding the grieving process, Ensure individual and family understand that feelings of grief are “normal” under the circumstances</td>
<td>Use supports to reduce fear, Communicate feelings of comfort and understanding, Develop or refine coping strategies that enable them to adapt to the demands of the illness without destroying family balance</td>
</tr>
<tr>
<td>Anger</td>
<td>Diagnosis of a chronic illness</td>
<td>Provide family and individual with outlets for expressing anger, Educate family and individual on behaviours that restrict exaggerated emotional responses</td>
<td>Vent anger in a positive fashion</td>
</tr>
<tr>
<td>Fear</td>
<td>Related to the uncertainty of future events</td>
<td>Educate family on disease process</td>
<td>Demonstrate an improved understanding of the disease process, Fear future events less</td>
</tr>
</tbody>
</table>
### Guilt

**Disease pathogenesis or process itself**

- Allow expression of guilt
- Provide reassurance
- Ensure individual and family understand that feelings of guilt are “normal” under the circumstances
- Demonstrate an increased understanding of the disease process
- Acknowledge that guilt is an allowable emotion
- Understand that the individual acquiring the disease was no one’s fault

### List five interventions for individuals with financial difficulties.

1. **Examine the individual’s financial needs and how well these needs are currently being met**
2. **Discuss the availability of alternate financial support (e.g., family, friends, benefits, occupational pension)**
3. **Inform individual of possible eligibility for financial assistance, e.g. disability allowance, incapacity, income support, etc.**
4. **Refer individual to financial assistance services e.g. CIC, Welfare Rights**
5. **Inform individual of Disability Rights Act 1996 and Citizens Information Centre/Department of Social Welfare.**
### 5.11 GLOSSARY

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>CNSp</td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
</tr>
<tr>
<td>MS</td>
<td>Multiple sclerosis</td>
</tr>
<tr>
<td>PHN</td>
<td>Public Health Nurse</td>
</tr>
<tr>
<td>PWMS</td>
<td>People with multiple sclerosis</td>
</tr>
<tr>
<td>RRMS</td>
<td>Relapsing remitting multiple sclerosis</td>
</tr>
</tbody>
</table>