

BLOCK SWH. 104 COMMUNITY CARE

Contents

A.	HISTORY AND BACKGROUND OF COMMUNITY CARE			
	1. Definitions of Community Care	Į.		
	2. History of Community Care	(
	3. Key Legislation	(
	4. Care Management	7		
	5. The Carers (Recognition and Services) Act 1995	ç		
	6. Planning for Community Care	10		
	7. Relationship Between Health and Social Services	10		
	8. Culturally Appropriate Services	12		
В.	MENTAL HEALTH AND COMMUNITY CARE			
	1. What Is Mental Illness?	16		
	2. Types of Mental Illness	18		
	3. Explanations of Mental Illness	20		
	4. Treatments	2		
	5. Services for People with Mental Health Problems	25		
C.	MENTAL HEALTH AND THE LAW	28		
	1. Mental Health Act 1983	28		
	2. Mental Health and the Criminal Justice System	2		
D.	OLDERPEOPLE			
	1. Demographics	30		
	2. Assessing the Needs of Older People	30		
	3. Residential Care	3		
E.	LEARNING DISABILITY	38		
	1. Definitions	33		
	2. Meeting the Needs of People with Learning Disabilities	34		
	3. An Ordinary Life	38		
	4. Advocacy and Self Advocacy	36		
	5. Carers and Their Needs	37		
	6. Disability	38		
E.	HOUSING ISSUES IN COMMUNITY CARE	39		
	1. Introduction	39		
	2. Housing Services and Innovation in Community Care	40		
	3. The Future Role of Housing in Community Care	4		
AN	SWERS	44		
	PENDIX 1: Information for Carers from Hampshire County Countsweb website)	ıncil 4		
ΑPI	PENDIX 2: Young Carers Information	48		

Preface

In this Block, we will be reviewing the history of the concept and practice of care in the community as it affects a number of different groups of people within society.

Community care is not a new idea, but the last twenty years have seen major changes in the legislation that underpins it and in the organisations which provide it. The implications of the NHS and Community Care Act 1990, the Carers Act 1995, the Health Act 1999, the NHS Plan, and the Health and Social Care Act 2001 will be considered.

We will then go on to look at some of the groups who need community care services: people with mental health problems, older people, people with learning disabilities and people with learning disabilities.

Finally, we will look at the growing role of housing providers in the delivery of community care.

Outcomes

After completing this Block, you should be able to:

- examine the history of community care development and evaluate its success in relation to the housing needs of a particular group of people in society;
- review the community care elements of the Health Improvement Plan for the local area and examine this in relation to consultation over housing needs and preferences.

A. History and Background of Community Care

In this section, we will look at the broad definition of community care, its historical roots relevant legislation and the ways in which Social Services Departments and the NHS collaborate to plan for the community care needs of their populations.

The Concepts

1. Definitions of Community Care

Activity 1

What is your personal definition of "community care"?

Comment:

There is no single definition of community care. For some people, it is care in the community, but provided largely by professionals. For others, it is care by the community, provided largely by neighbours, friends and families. For some, the phrase is most closely associated with the policy of closure of large psychiatric hospitals and the release of long-stay patients into the community. It has even begun to have some currency as an insult, as in "If you believe that, you need care in the community".

Put simply, community care is the care that you need to enable you to live at home and enjoy the sort of choices and freedom over your life experienced by the majority of citizens in our society. Living a fulfilling life at home does not normally present a problem for those who are well and able-bodied, or who can count on support from family or friends and neighbours. Others may be able to pay for the help they need.

For some, though, living at home is difficult if they are frail, disabled or vulnerable and lack the means to pay for the support they need. The question of how society involves itself in the lives of such people is at the heart of debates about community care.

One concept that needs to be explored in this context is the term "community" itself. What do we mean by "community"? Do we hark back to a golden age of communities which all pulled together, or do we take the Margaret Thatcher view that "there is no such thing as society"? When we talk about people being cared for in or by the community, who or what is the community doing the caring?

2. History of Community Care

The history of community care is also to a large extent the history of the poor. When the poor became ill or disabled, they were unable to remain at home and were forced to live in institutions such as almshouses or later workhouses and asylums. Institutionalisation was the response of public authorities to those who could not obtain the care and/or financial support they needed. One example of this institutionalised care would be the workhouse system as described in the Block on Poverty. The history and function of long-stay hospitals will be discussed later in this Block.

The dominant concept relating to community care at present is that found in the NHS and Community Care Act 1990. This defines the roles and responsibilities of local authorities in relation to people with care needs, and places emphasis on the right to an assessment of need and the right to live independently wherever possible.

3. Key Legislation

There are many laws which, since the foundation of the Welfare State in the period immediately following World War II, have defined the roles of public authorities in relation to care in the community. Some of these, such as laws relating to mental health and disability, will be discussed later in the Block. At present, however, we need to concentrate on the laws which currently inform community care in general: the NHS and Community Care Act 1990 and the Carers (Recognition and Services) Act 1995.

The NHS and Community Care Act 1990 was a major Act of Parliament which set out to revolutionise the way in which care in the community was delivered. The key principles were:

- an emphasis on planning and the requirement to produce, in consultation with other agencies and community representatives, a Community Care Plan for their area;
- the separation of the roles of purchaser or commissioner of care from that of provider of care (as discussed elsewhere in this Unit);
- the introduction of an approach to community care known as Care Management.

4. Care Management

The White Paper Caring for People (Department of Health (1989) Caring for People: Community Care in the Next Decade and Beyond, HMSO) which preceded the NHS and Community Care Act 1990 spelt out five functions of care management. These are:

(i) Identification of need

This relates to the wider function of the local authority in obtaining information about the level and type of need in their area and planning to meet that need.

(ii) Assessment of care needs

This brings the process down to the level of the individual service user. An assessment can be simple or complex. A complex assessment might involve collaboration between a number of agencies and different professionals.

(iii) Planning and securing the delivery of care

This may involve slotting the service user into an existing service arrangement such as the provision of domiciliary care, or it may involve an individually-tailored "care package", for example, finding a Polish-speaking care home for a Polish-speaking service user.

(iv) Monitoring the quality of care provided

This happens at a number of levels. At the level of the individual service user, it would involve reviewing the effectiveness of the care package in meeting the individual's needs. It is important that the voice of the service user is heard as a part of this process. There is another level of monitoring which is about monitoring the effectiveness of service agreements drawn up between the local authority (purchaser or commissioner of care) and the various bodies which provide care, whether their own in-house services or independent sector providers.

(v) Review of client needs

People's needs are not static. People change and develop or deteriorate, and therefore their care needs may change. One unfortunate feature of the system that precede the NHS and Community Care Act 1990 was that once people were slotted into a service such as a residential home, then their cases were closed

Α	Cī	IV	ITV

Below is a list of professionals who may be involved in the care management process. How might each contribute to the assessment process?

Practitioner	Contribution to assessment
Social Worker	
GP	
Community Nurse	
Housing Officer	
Benefits Agency	
Occupational Therapist	

Comment:

You might have identified some of the following:

- GP assesses and responds to health care needs
- Social worker assesses social care needs and coordinates the care management process
- Community Nurse may play a key role in assessment where health needs are a major factor
- Housing Officer may contribute to the assessment by identifying housing needs and options available
- Occupational Therapist assesses the person's skills in independent living and identifies the assistance which can be given to promote independence

5. The Carers (Recognition and Services) Act 1995

Central to the concept of care in the community is the role of the so-called "informal carer" Indeed, some early critics of the NHS and Community Care Act 1990 argued that the working of the new approach depended on the unrecognised work of family members and neighbours. The Act is an attempt to acknowledge the key role played by informal carers and to recognise that they too have needs.

If we assume the typical user of community care services is an older person who is physically and probably mentally frail, it will be obvious that a spouse, who is often the main carer, is likely to have needs of their own which should be met in order to enable them to carry on caring.

The Carers Act entitles the carer to an assessment of their own needs if they request it. Good practice suggests that for this to be effective, the local authority must be diligent about providing readily accessible information. Appendix 1 shows the information for carers which is provided on the Hampshire County Council website.

The Act also recognises the existence and special needs of young carers. They should normally be considered as children in need under the **Children Act 1989** and there needs to be good liaison between those who assess the needs of the child or young person and those who assess the needs of the person they are caring for. Appendix 2, again from Hampshire County Council, shows the information that the Social Services Department provides on its services for young carers.

How is care provided?

Once an assessment of need has been made, then the usual practice is for the social worker or care manager to purchase a package of care. This might involve arranging domiciliary or residential care, help with activities of daily living, day or respite care. These services may be purchased either from the local authority's own in-house service providers, or from the independent sector.

There is also provision for service users to receive the money to purchase their own care packages rather than rely on social services to purchase for them. The funding may come entirely from the Social Services budget, or where care costs are likely to be high, applicants may also need to apply to a central fund called the Independent Living Fund. The advantage of this scheme is that it enables people to have almost complete control of their care package (though obviously they must be able to show that they are spending the money on their care package). It is an ideal scheme for some people, but for others it may prove too complex as they are required to find their own care providers and act as their employer with all the obligations this entails. For information provided on this scheme by one local authority, see http://www.hants.gov.uk/socservs/directpayments/hdps.html.

6. Planning for Community Care

The NHSCCA required local authorities to produce a community care plan for their area. In order to do this, they were expected to consult widely with other agencies, service users and carers, and with representatives of the independent sector. The requirements on community care planning are currently being reviewed since the Health Act 1999 required Health Authorities to produce a Health Improvement plan which covered some of the same ground. Despite this, the fact remains that **planning** for community care is a vital function of both health and social services.

7. Relationship between Health and Social Services

In order for community care to be effectively planned and delivered, it has become clear since 1990 that health and social services need to work closely together. This joint working has accelerated since the election of the Labour government in 1997, with its emphasis on "joined-up working". The **Health Act 1999** set up mechanisms for health and social services to pool their budgets for some services, and in many areas there have been jointly-funded teams set up with representatives of both health and social services on the workforce.

The NHS Plan of 2000 proposed a mechanism for taking this further by setting up joint Care Trusts, which would pool the resources of health and social services for the purposes of planning, commissioning and providing care services. The principle underlying this proposal is that service should be planned from the patient up, not from the agency down. In the past, people with complex health and social care needs have had to negotiate with the two separate agencies and this could make their lives unnecessarily complicated. The classic example of this is the distinction between medical and social baths. If a bath was deemed necessary for the care of a medical condition, then it was deemed to be the responsibility of the NHS. If the bath was just because the person needed to keep clean, it was seen as a social care need, the responsibility of social services. Of course, from the individual's point of view, they wanted a bath and did not care who provided it; still less did they care to become involved in an unseemly wrangle between the two agencies as to whose job it was.

The Health and Social Care Act, which was passed just before the 2001 election, provided the legal framework for the setting up of Care Trusts, although the original proposal to make such Trusts compulsory for "failing" local authorities was dropped before the final readings.

Care Trusts are NHS organisations that provide health and social care to a particular population. The local authority delegates the responsibility for providing social care for an agreed population to the Care Trust but retains overall accountability for services. The Care Trust also provides healthcare services for this group of people. This means that there is one organisation dealing with an individual's social and health care needs, resulting in a more integrated service. As the local authority devolves its budget for social care services to the Care Trust, all health and social services are funded from a single source. This overcomes one of the main obstacles to previous attempts at partnership working in this area. If all social and health care services are being funded from a single budget, the argument over when social care becomes healthcare is avoided and there is greater potential to provide more social care in order to reduce the need for healthcare services. There are also benefits for staff. If all staff are working for the same organisation and based in the same place, there is greater scope for multi-disciplinary working and training. The initial focus of Care Trusts has been on older people and those with mental illnesses. However, their work does not have to be restricted to a particular client group.

8. Culturally Appropriate Services

It is important to take account of a person's cultural background when assessing their need for services and providing social care. People's religious, ethnic and cultural background can influence their perception of their circumstances and their need for services. One a simple level, this may mean making special arrangements to cater for people's dietary requirements, for example, providing halah or kosher meals. However, in many cases people's religious beliefs and cultural norms will influence all aspects of their care package. Some cultures have strong views about interactions between men and women. This may mean that people are uncomfortable about receiving personal help from people of an opposite gender. Many cultures have very strong family connections and support networks. As a result, some people and their carers may perceive needing social care services from outside agencies as a failure of their personal informal support networks. Care must be taken to work with the individual and their carers to ensure that these issues are dealt with sensitively and the final package of care is acceptable to the client.

Some housing organisations that are working in areas where there are significant minority communities have developed housing schemes that cater specifically for particular groups with social care needs. Agudas Israel Housing Association is based in Hackney, London and provides housing mainly for the Orthodox Jewish population in the area. They have built a complex that provides housing and social care for older members of the community. The complex provides a varying degree of social care depending on people's needs. All care is provided in a way that acknowledges people's religious beliefs and cultural values. A small synagogue is attached to the complex that allows residents to continue to attend services.

Activity 2

Obtain a copy of the health improvement plan for your area. In addressing community care needs, what consultation was undertaken?

Seli	f Test 1
1.	Which legislation defines the current system for providing care in the community?
2.	What are the rights of carers?
3.	Which two agencies share responsibility for planning community care?

B. Mental Health and Community Care

Activity 3

In 1999, a young man with a long history broke into the house of the former Beatle George Harrison and inflicted life-threatening injuries on him. He was found not guilty by reason of insanity and committed to a secure psychiatric hospital.

The young man's family reported that he had been experiencing many psychological symptoms for some time (e.g. hearing voices and having delusions), but they had had difficulty in obtaining appropriate care and treatment for him.

What is the effect of high-profile cases like this on the public's perceptions of people with mental health problems?

Comment:

There have been numerous media accounts of people with mental health problems who have been involved in attacks on people. This contributes to a public perception that people with mental health problems are inherently dangerous. However, these cases are, in fact, rare, though distressing when they occur. Some of these incidents may be seen as highlighting an apparent failure of health and social services to provide appropriate care for people with severe mental health problems.

1. What is Mental Illness?

This is not as straightforward a question as it might first appear. 250 years ago, the concept of mental illness was not generally recognised in the UK. In mediaeval times, and as late as the 17th century, people displaying behaviour associated with psychiatric symptoms would often be regarded as suffering from demonic possession. The treatment of choice would have been exorcism.

Large-scale institutional treatment of mentally ill people began around the 18th century. Private "madhouses" were founded, where people were often kept in chains and shackles.

The most famous of these institutions in England was "Bedlam", the Bethlem Hospital. Fashionable people used to visit Bedlam on a Sunday to be entertained by the behaviour of the "madmen".

Peterson (*A Mad People's History of Madness*, University of Pittsburgh Press, 1982) brings together various historical accounts written by the inmates of mental institutions from the 15th century onwards. In one of these, Samuel Bruckshaw describes his admission to a private madhouse in 1774 as follows:

"When Wilson showed me to bed, he carried me up into a dark and dirty garret, there stripped me, and carried my clothing out of the room, which I saw no more for upwards of a month, but lay chained to this bad bed, all that time. This appears to be the breaking-in garret ... At the end of the month, I was permitted to have my clothes for a day and to walk about the house in irons."

Legislation to regulate the treatment of people with mental health problems began in a small way in the late 18th century. By the mid-19th century, the Lunacy Acts had required each county to provide an asylum and to inspect the treatment provided in that

asylum. The word 'asylum' originally meant a place of refuge, and the choice of this term reflects a slight lessening of the harshness of the regimes of the old madhouses. The law was increasingly seeing people with mental health problems as sick and in need of rest and medical treatment.

The asylums were, by and large, built in isolated country areas where the mentally ill could be safely contained away from large centres of population. Many of these hospitals continued to house people with mental health problems and learning disabilities until the 1990s.

In the post-war period, as the Welfare State began to develop, questions were being asked about the appropriateness of this type of institutional treatment for large numbers of people with mental health problems.

The 1959 Mental Health Act contained some provisions that encouraged treatment in the community, and this was further developed in the 1983 Mental Health Act and the NHS and Community Care Act 1990.

What caused these changes? There are a number of different strands to be unpicked if we are to understand changing approaches to mental illness.

- The growth of "scientific medicine": changes in the way diseases, including diseases of the mind, were classified.
- The development of new drugs: In the 1930s, the vast majority of long-stay patients were either suffering from the final stages of syphilis or from schizophrenia. The development of antibiotics to treat syphilis stopped this sexually-transmitted disease from reaching the brain; the development of the major tranquillisers such as largactil reduced some of the extreme symptoms of schizophrenia and made it more feasible for people with schizophrenia to live in a less restrictive environment.
- The development of psychology: from Freud's study of the unconscious, to the work of behavioural and cognitive psychologists, psychology has attempted to understand the workings of the mind and to attempt to find solutions to psychological problems.

2. Types of Mental Illness

While we need to understand some of the more technical medical terms and diagnoses, we should avoid relying on a purely medical model. The National Service Framework (see below) reflects more of a whole person approach to people with mental health problems by its use of the term "severe and enduring mental illness". This term suggests that we should focus on the experiences and needs of the "patient", rather than just on their medical diagnosis.

Historically, mental illnesses have been classified as *psychotic* or *neurotic*.

In broad terms, a person is seen as having a psychotic illness if their condition causes some sort of loss of touch with reality such as hallucinations or delusions.

A person would be considered as having a neurotic illness if they remained in touch with reality despite their distress.

Some of the main diagnostic labels you are likely to come across include:

	Description	
y disorder	Anxiety disorders take several forms. An extreme form would be the Activity 4: Effects on phopie's ability to live in the other physical symptoms associated with acute fear. Other people Given the nignificant and injection described hims free the tarble of problems unignetipe of leutivith nilles and obtains free thrution. The first is attached to a particular stimulus such as flying or spiders, are also part of the spectrum of anxiety disorders.	above, what
essive-compulsive disorder	This type of condition often presents with a morbid fear of dirt. An affected person may ritually clean their home or their own body numerous times in a day. Attempts to stop this ritualised behaviour will result in acute anxiety.	
rsonality disorders	This is a controversial term. It is usually applied to people who do not have a recognised illness, but whose behaviour falls outside what society accepts as "normal". For example, a person may have an incompletely developed sense of right and wrong, or they may be highly suspicious and/or find it very difficult to mix with other people.	
ntal illness with a known vsical cause such as heimer's disease and other ms of dementia	In Alzheimer's disease, a degenerative condition of the brain causes loss of memory and other mental functions. As mentioned above, many in-patients up to the 1930s were suffering from the final stages of syphilis, where the infection affected the brain. This is now	
	extremely rare because antibiotics can treat the infection before it progresses this far.	

Comment:

While our attention is often drawn by the more florid symptoms such as delusions, in fact the major difficulties faced by people with mental health problems living in the community are not that different from those experienced by many other people. Depression and social isolation often form a stronger barrier to successful life in the community than do delusions or hallucinations.

3. Explanations of Mental Illness

(a) Physical explanations

Psychiatric symptoms can be caused by physical damage to the brain, such as that experienced by people with Alzheimer's or other dementias. Some authorities believe that biochemical imbalances in the brain can cause a whole range of symptoms.

For example, the use of the newer anti-depressants such as Prozac is based on the premise that depression is associated with low levels of the brain chemical serotonin. Prozac is a selective serotonin reuptake inhibitor, which is designed to keep serotonin levels higher.

Twin studies have shown that if one identical twin has schizophrenia, the other has a significantly higher chance or developing it than other siblings or even non-identical twins. This has led some psychiatrists to the conclusion that there is a significant genetic component in schizophrenia.

(b) Emotional explanations

Freud was the originator of psychoanalysis, whose main explanations for mental illness were based on the role of the unconscious and on early experience. While full-blown Freudian psychoanalysis did not have the same impact in the UK as it did in the USA, neo-Freudians such as John Bowlby have had a major impact on psychological thinking in this country. Bowlby's studies of the effects of separation or maternal deprivation on young children have been influential in shaping policy.

(c) Behavioural explanations

This category of explanations derives from the idea that behaviours are learned. So, for example, a small child learns through a process of trial and error, reward and punishment, that it is in her best interests to learn to use the potty. Similarly, if older siblings chase a small child and repeatedly pretend to put a spider down the back of her neck, she is likely to develop a phobia about spiders.

Behavioural theories also incorporate cognitive-behavioural theories. For example, Ellis, one of the founders of "Rational Emotive Therapy", argued that irrational beliefs can form the basis of depression. For example, a depressed person would believe that they are a bad or worthless person. (Ellis, *Reason and Emotion in Psychotherapy*, Lyle Stuart, 1962.)

(c) Sociological explanations

Some explanations for the origins and incidence of mental illness derive from sociology. Sociologists have noted that the incidence of schizophrenia is higher in the most disadvantaged social groups. Moore notes that studies in both the US and UK have shown that around 20% of homeless people have experienced significant mental health problems. (Moore, *Social Welfare Alive*, Stanley Thornes, 1998.) The question then arises: do deprivation and social exclusion **cause** mental illness, or do people **become** socially excluded when they experience mental health problems?

4. Treatments

Treatments can be divided broadly into physical treatments and psychological treatments.

Physical treatments include:

- Medication such as anti-depressants or anti-psychotics.
- Electro-convulsive therapy (ECT) This involves applying an electric current through the brain. This simulates some of the effects of an epileptic seizure, although because the patient is anaesthetised they do not show other effects such as jerking of the limbs.

Effects of physical treatments

No medication is without side-effects, and no medication can claim to be a "magic bullet" with the ability to cure all ills. Over the years, many drugs have been introduced to treat psychiatric symptoms. Many of these drugs have left casualties in their wake.

For example, in the early 1960s, a new class of drug was developed to treat anxiety disorders. These were the benzodiazepines, of which Valium was probably the best known (though the family of drugs also includes such drugs as Temazepam which is a major drug of abuse in some areas). Valium and its relatives were widely prescribed in the belief that they were problem-free, and it was not until the 1980s that prescribers became aware of the very real problem of dependency.

People with bipolar affective disorder may be prescribed Lithium, which can be highly effective in levelling out mood swings. However, lithium is a heavy metal and patients must be closely monitored to ensure that toxic levels do not build up in the bloodstream.

In the 1950s, anti-psychotics such as Largactil and long-acting versions such as Depixol were developed. These drugs could be said to have laid the groundwork for community care. With severe delusions and other psychotic symptoms under control, schizophrenia no longer progressed to the extent where people with the condition became "burnt-out". However, the drugs are by no means without side effects. There are many disabling physical symptoms that can arise from the use of these drugs. Some people develop shaking and other symptoms akin to Parkinson's disease. The side-effects then need treating with other drugs, which in turn have their own side effects.

In the first half of the 20th Century, there were a number of other physical treatments used to treat major mental illnesses. Some patients were given insulin to produce a coma, others were wrapped in cold wet sheets. In the 1950s, brain surgery was used quite extensively. The only one of these non-pharmaceutical physical treatments which remains in widespread use is ECT. ECT was originally used to treat schizophrenia because it was believed (wrongly as it turned out) that people with epilepsy never developed schizophrenia) The logic, therefore, was that if you gave people a simulated epileptic fit, you could arrest the progress of their schizophrenia. Its major use now is in the treatment of depression, where the condition is so severe as to be lifethreatening.

Psychotherapy and other non-physical treatments

Most people diagnosed as having a mental illness receive physical treatment only. Psychotherapies of various types are available on the NHS, but only to a minority of patients.

The people most likely to receive "talking treatments" such as psychotherapy are articulate middle class white people with mild to moderate symptoms

5. Services For People With Mental Health Problems

The move towards care in the community for more people with mental health problems began in the late 1950s, and grew in momentum from the 1980s, when many long-stay patients were gradually returned to live in the community. The motivation for this development could be one of two things, depending on how cynical you are:

Humanitarian motive: It is an offence against basic human rights to keep people incarcerated and excluded from participation in the life of the community.

Economic motivation: Cynics among us may conclude that it is extremely expensive to keep people locked up in large institutions. In the USA, the closure of State hospitals often resulted in people being discharged from hospital to live in the subway or on the streets. It is a bit of a stretch to call this community care.

If community care is going to work, it must be supported by community services. With this in mind, a National Service Framework has been developed for Mental Health. The NSF presents 7 standards. Each Standard lays down the level of service which is expected, who is responsible for delivering it, and the mechanisms for monitoring it.

Standard	Level of Service	Lead Agency	Key Partners
1. mental health promotion	Promote mental health for all Combat discrimination	Health Authority	PCGs, local authority, education, independent sector providers, users and carers
2. primary care	Assessment of mental health need Offer of treatment/referral	PCG	Primary Care teams, LA, NHS Trust, independent sector providers, users and carers
3. access to services	Round the clock access Able to use NHS Direct	PCG	Primary Care teams, LA, NHS Trust, independent sector providers, users and carers
4. community services (severe mental illness)	Written care plan, reviewed by a care coordinator Round the clock access	NHS Trust	PCGs, local authority, health authority, independent sector providers, users and carers
5. care away from home (severe mental illness)	Access to bed which is in least restrictive environment possible and as close to home as possible Written care plan on discharge	NHS Trust	PCGs, local authority, health authority, independent sector providers, users and carers
6. Caring about carers	Assessment of need Own written care plan	Local authority	PCGs, NHS Trust, health authority, independent sector providers, users and carers
7. Suicide Prevention	Links to other six standards, plus: Support to prison staff Risk assessment, suicide audit		PCGs, local authority, criminal justice agencies, independent sector providers, users and carers

Monitoring the NSF:

The achievement of the standards will be monitored through a range of local and national activities. These include:

- National Psychiatric Morbidity Survey
- · National surveys of users and carers
- Monitoring suicide rates

Delivering the NSF: the Care Programme Approach

The Care Programme Approach is not new, but it has recently been revised (or modernised as the government likes to call it). Not all areas had successfully implemented the CPA, but the new guidelines incorporate strict monitoring from the Department of Health.

The CPA outlines services that should be available to adults under 65 who have severe and enduring mental illness.

The cornerstone of the CPA is that each person should have a written care plan which sets out the services they have been assessed as needing and how those services will be provided. Each person on the CPA should have a named care coordinator, who is responsible for monitoring the progress of the plan and coordinating all the agencies and professionals involved

C. Mental Health and the Law

Mental Health Act 1983

Provisions for compulsory admission and treatment

While the Act, like the 1959 Act before it, makes provisions for community care, it also lays down the conditions under which people can be compulsorily admitted either for their own protection or that of the wider community. While it is not useful to go into the details here, some of the main conditions are outlined below:

Under **Section 2** of the Act, a person can be compulsorily admitted (sectioned) at the request of the nearest relative or a suitably qualified social workers. Two doctors' signatures are required.

Section 3 allows compulsory treatment to be extended to six months.

Section 117 gives the relevant agencies powers to provide after care for those released following compulsory admission.

The Act defines the powers of the specialist mental health social worker (Approved Social Worker). The ASW normally coordinates the admission process, and is required by law to ensure that the patient is "appropriately interviewed" (this raises issues about how people whose first language is not English would be interviewed). The ASW must also ensure that compulsory admission is the only viable option, i.e. that there are no appropriate community services and that the patient will not consent to voluntary admission. In order to carry out the role of ASW, social workers must undertake a prescribed form of post-qualifying training.

The Mental Health Act Commission is charged with monitoring the use of the Act, and also has Tribunals which hear appeals against orders.

Following on from the 1983 Act, a new order was created in 1995. The supervised discharge order can compel discharged patients to live at specific addresses and to accept certain forms of treatment.

A draft Mental Incapacity Bill was published in June 2003. At the time of writing (Summer 2004), it was before Parliament and had been renamed the Mental Capacity Bill. The Bill provides a framework to protect vulnerable people, their carers and professionals. It sets out how decisions should be made affecting the care and treatment of people with mental illnesses. The underlying principle of the Bill is that an individual has the capacity to make decisions relating to their care and life and that practical steps should be taken to help them make such decisions. The Bill is underpinned by a set of five key principles stated at the front of the Bill. These are:

- a presumption of capacity every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise;
- the right for individuals to be supported to make their own decisions people must be given all appropriate help before anyone concludes that they cannot make their own decisions;
- that individuals must retain the right to make what might be seen as eccentric or unwise decisions;
- best interests anything done for or on behalf of people without capacity must be in their best interests; and
- least restrictive intervention anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

The Bill sets out a single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time. It is a "decision-specific" test. No one can be labelled 'incapable' as a result of a particular medical condition or diagnosis. Everything that is done for a person who lacks capacity must be in that person's best interests. The Bill provides a checklist of factors that decision-makers must work through in deciding what is in a person's best interests. The person themselves - their wishes and feelings - and their participation are key factors. Carers and family members also gain a right to be consulted on key decisions. Where an individual is not capable of making a decision for themselves and there is no one to make on their behalf, an independent consultee will be appointed. This independent consultee would assist in making decisions in relation to serious medical treatment and long term residential care. It is also intended that the independent consultee would be involved in an annual review of the individual's care. The Bill also introduces a new criminal offence of ill treatment or neglect of a person who lacks capacity. A person found guilty of such an offence may be liable to a term of up to five years imprisonment.

The Bill also enables people to plan ahead for a time when they may lose capacity to make decisions for themselves. Rules with clear safeguards will be introduced to allow people to make a decision refuse medical treatment if they lose the capacity to make decisions for themselves at any point in the future. A Lasting Power of Attorney will also be introduced. This is like the current Enduring Power of Attorney that allow people to nominate someone to manage their financial affairs if they are unable to do so. However, the Lasting Power of Attorney allows a nominated person to make decisions relating to the health and welfare of the individual.

2. Mental Health and The Criminal Justice System

It is reported by Moore (op.cit. 1998) that up to 20% of the prison population have mental health problems, and many more have drug or alcohol-related problems. It is interesting to note that the powers of courts to order people to be detained under the Mental Health Act are disproportionately applied with offenders from black and minority ethnic groups

Comment:

Many housing providers, particularly housing associations, have developed a range of housing options for people with mental health problems. Depending on the assessment of need, these can range from hostels, through supported housing with a high level of staff input, to independent accommodation.

Such arrangements are part of the partnership approach between health, social care and housing which underpins so much of current practice.

D. Older People

Warning

by Jenny Joseph

When am an old woman, I shall wear purple With a red hat which doesn't go, and doesn't suit me,

And I shall spend my pension on brandy and summer gloves And satin sandals, and say we've no money for butter.

I shall sit down on the pavement when I'm tired And gobble up samples in shops and press alarm bells And run my stick along the public railings And make up for the sobriety of my youth.

I shall go out in my slippers in the rain And pick the flowers in other people's gardens And learn to spit.

You can wear terrible shirts and grow more fat And eat three pounds of sausages at a go Or only bread and a pickle for a week And hoard pens and pencils and beermats and things in boxes.

But now we must have clothes that keep us dry And pay our rent and not swear in the street And set a good example for the children. We must have friends to dinner and read the papers.

Maybe I ought to practise a little now? So people who know me are not too shocked and surprised.

The poem above was recently voted the most popular poem in Britain. What does it tell us about the writer's attitude to the process of aging?

What are your own expectations of old age?

What values do you think your community holds about older people?

Comment:

The poem shows a person who wants to reject some of the stereotypes that seem to surround ageing in the UK. Older people are not expected to be bolshy. They are often seen as frail, passive, dependent. But in fact the majority of older people live completely independent lives in their own homes

1. Demographics

The UK has an aging population. It is expected that by the middle of the 21st century approximately 25% of the population will be above retirement age.

There are a number of reasons for this growth in the proportion of older people in the population:

- The "baby boomers" (the people born as part of the population explosion in the years immediately after World War 2) are beginning to reach retirement age, and the birth rate has fallen since.
- Life expectancy has increased considerably throughout the 20th century.

Is this a problem? It can certainly be seen as a problem if we look at what is often called the "dependency ratio". This is a figure which compares the proportion of retired people with the proportion of working taxpayers. It is projected that by 2051 there will be 43 retired people for every 100 people of working age (*Social Trends*, HMSO, 1994). Is it reasonable to assume that the taxes paid by the working-age population would be sufficient to support the retired population.

However, this approach raises the question of whether we are right to see older people as being necessarily dependent. Perhaps the changing age structure of the population will provide an incentive for us to re-examine the contribution that older people can make to society. Perhaps we will have to review whether it is desirable to have a compulsory retirement age.

2. Assessing The Needs Of Older People

Under the NHSCCA 1990, older people have a right to request an assessment of their needs. Depending on their situation, this assessment may be straightforward or complex, and may result in the provision of a simple service or a complex package of services to support community living.

In order to support older people living in the community, a range of services may be needed, e.g.:

- Home care
- Community Nursing Services
- Other Primary Care services, e.g. GP
- Day care
- Respite care (a short stay in residential care in order to give a break to the carer)
- Aids and adaptations to support activities of daily living (these would normally be provided by the Occupational Therapy Service, either from the NHS or the local authority)
- Alarm service (to call in an emergency)
- Housing improvements
- Sheltered or supported housing

3. Residential Care

Many older people wish to remain independent in the community for as long as possible. However, frailty, loss of mobility or the onset of conditions such as dementia may mean that this is no longer viable. In these circumstances, residential care may be needed.

There are two types of residential homes:

Care homes: the need for admission to these homes is assessed by the local authority social service department. Homes are subject to inspection and registration by the local authority. Residents are liable to pay for their care if they have resources above a certain level.

Nursing homes: the need is usually jointly assessed by health and social services. Homes are subject to inspection and registration by the Health Authority A recent decision by the Department of Health means that residents are no longer expected to pay for the nursing component of their care, but they are still expected to pay for their board and lodging.

Note: The government proposes to remove the inspection and registration function from individual health authorities and local authorities, and to locate them instead in Regional Commissions for Care Standards.

Activity

What are the arguments for and against older people paying for residential care services?

Comment:

You may consider that it is unfair to make people sell their family home and use up all their hard-earned savings in order to pay for their care.

On the other hand, it can be argued that if people were living at home they would have to pay for their food and other living expenses, so why should they not do so in residential care? Furthermore, some people would argue that if homes are protected, then the people who will gain will be, not the old people themselves, but their offspring who stand to inherit. Should the taxpayer pay for someone to protect the inheritance of their children?

E. Learning Disability

1. Definitions

Just as we saw in relation to mental illness, the language used to describe and define learning disabilities show how attitudes have formed and developed. Words like "moron" and "imbecile", which are now only used as terms of abuse, used to constitute legal definitions. In the early part of the 20th century, people with learning disabilities were legally defined as "mentally defective". The 1959 Mental Health Act replaced these terms with "educationally subnormal", but it was not until the 1971 Education Act that the ability and right of all people with learning disabilities (or "with special educational needs", as the Act defined it) were recognised.

Activity

What are your own responses to some of the language used to define learning disabilities in the past?

What are the terms currently in use? Why do many people prefer these terms?

Comment:

You may be appalled by the fact that insulting terms such as "moron" or "subnormal" were once enshrined in legislation. However, terms like "mental handicap" are also experienced as offensive by many people with learning disabilities. Can you put your hand on your heart and say you've never used this or other socially excluding language?

2. Meeting The Needs Of People With Learning Disabilities

For most of the 20th century, the approach to the care of people with learning disabilities was institutional care in large hospitals, often outside towns.

In the 1980s, the process of emptying these large institutions began, partly because of changing attitudes and partly at least because of a series of scandals about the ill-treatment of patients. Many of the people who came out of the large "subnormality" hospitals had been there for 30 or 40 years, and it was not uncommon to discover that the reason for their incarceration was a judgment that they were "morally defective" in the terms of the 1913 Mental Deficiency Act. Young girls had been locked away because they had a baby outside of wedlock or were believed to be promiscuous; young boys were deemed morally defective for minor offences of theft.

In the latter part of the 20th century, the approach to the care of people with learning disabilities was based on the principle that people had rights, including the right to ordinary lives (see below).

Government gave financial support to the development of care in the community, helping people move from large institutions to smaller community homes and for some people ultimately into independent or semi-independent living in ordinary houses and flats.

People with learning disabilities have a right to remain in full-time education until they are 19. For those over 19, a range of options are available. Many people attend colleges of further education, while others may attend a day centre or Social Education Centre. These centres, run by local authority social services, used to offer a very limited service: people were often occupied with meaningless or menial tasks such as packing, for which they were paid very small amounts of money. Nowadays, the approach is more about developing life and social skills and preparation for employment.

3. An Ordinary Life

Activity

Place these things in order according to how much value you place on them.

The right to privacy

Choice of sexual partner

Ability to work for your living

Being able to choose what you have to eat

Being able to choose to go on an outing

Being able to choose where you live

Being able to choose your own clothes

Having access to your own money

How many of these things are normally available to people with a learning disability?

Comment:

Many of these things are ordinary activities which we may take for granted, but they are not always readily available to people with learning disabilities. For example, how many of us had to undertake some form of "training" before we were able to live independently in our own homes?

"Normalisation"

This approach was developed in the 1970s. by Wolfensberger. Its key principle was that people with learning difficulties should be enabled to live as normal a life as possible. At the time, this was a valuable counterweight to the prevalent approach of isolating people with learning difficulties in institutions. However, for some people, the term "normalisation" itself presented some problems.

Who decides what is "normal"? Does normalisation impose the standards of non-disabled people on those with learning disabilities? What does it offer to people whose norms may differ from those commonly accepted in the society?

As a response to these criticisms and anxieties, Wolfensberger developed his principles and replaced the term "normalisation" with the (more appropriate but perhaps less user-friendly) term "social role valorisation" Social role valorisation means enabling people with learning disabilities to adopt socially valued roles in the community.

For this to happen, work needs to take place on two fronts:

- helping people with learning disabilities to develop the skills needed to live socially valued lives in the community;
- helping society, both lay people and care professions, to change their attitudes to people with learning disabilities.

Of course, some people with profound and multiple disabilities, or those whose learning difficulties are accompanied by challenging behaviour, may never be able to live independent lives, and will continue to need residential care. However, the circumstances in which that care is provided should be the least restrictive possible, and should incorporate the maximum possible amount of choice for residents.

Where learning disabilities are profound, then there is a challenge to the carer. How do we devise ways in which choices can be expressed, for example if the person has no speech? Solutions to this situation can include the use of the sign language *Makaton*, picture boards for people to indicate whether they are happy or unhappy, etc.

4. Advocacy and Self-Advocacy

One of the major developments in learning disabilities in the later years of the 20th century was the development of advocacy and self-advocacy. As seen above, people with learning disabilities need to develop skills in expressing their beliefs and choices if they are to take their place in society.

For those whose disabilities are profound, they may need someone else to act as their advocate, and many voluntary organisations have set up advocacy schemes whereby trained staff or volunteers work with the person to establish their wishes and help them express them to carers or social welfare agencies.

While the people most closely associated with the person with a learning disability may be the immediate family, it is not always appropriate for family members to represent their wishes, as their interests may sometimes conflict.

Self-advocacy takes this principle one step further. In self-advocacy, the person with a learning disability represents their own views, with or without assistance from an enabler. One of the best-known organisations in this field is *People First*. This national organisation is run by and for people with learning disabilities. An example of their work can be found in *Service Evaluation By People With Learning Difficulties*. This describes an evaluation of services for people with learning disabilities in the London Borough of Hillingdon. The services were evaluated by two consultants who had learning disabilities and were supported by a researcher from the King's Fund Centre. The results of the evaluation were welcomed by the local authority:

"The People First evaluation led the way in challenging traditional models, stereotypes and assumptions. It ... has given us a very clear reminder that our services are about people with very strong views about what they like and do not like ..."

(Source: Whittaker, Service Evaluation by People with Learning Difficulties, in Connor and Black, eds., Performance Review and Quality in Social Care, Jessica Kingsley, Chapter 8.)

5. Carers And Their Needs

The majority of adults with learning disabilities live with their parents. The life expectancy for people with learning disabilities has increased dramatically over the last few decades. One result of this is that increasingly, aging people with learning disabilities will be living with very elderly family members.

Walker and Walker (*Uncertain Futures: People with Learning Difficulties and their Ageing Family Carers*, Pavilion/JRF, 1998) researched the needs of this group of people, and their findings included:

- Need for practical information
- Need for professionals to work in partnership with carers
- Need for more flexible approaches to the needs of people with learning disabilities and their carers

Case Study:

Josie and John are both 28 years old. Josie has Down's Syndrome, while John's learning disabilities have no known cause. They met at the day centre which they both attend, and have been very close for over 5 years. John lives with his mother, who has encouraged their developing relationship. Josie's parents are strongly opposed to the relationship; they feel that Josie is like a child and are worried that she and John may be having a sexual relationship, which they believe is wrong for people with learning disabilities.

Josie and John have told John's mother that they have been having sex for some time now. They want to get married, have their own flat, and desperately want to have a baby.

What are your responses to this situation?

Comment:

Your responses to this activity may have made you ask yourself some serious questions about your own attitudes. Do you share some of Josie's mother's view that people with learning disabilities are "childlike"?

If you support Josie and John's rights to become parents, have you given consideration to the child's needs?

You might have considered that the Human Rights Act provides protection for the right to family life and to privacy. What impact might this have on Josie and John's situation?

6. Disability

Medical and social models of disability are discussed in the Health and Health Services Block. People with disabilities have also benefited from more emphasis being placed on their rights to live as independent citizens.

Local authorities are obliged to keep a register of people with disabilities in their area, and are able to provide a range of services to support independent living under the provisions of the NHSCCA and the Chronically Sick and Disabled Services Act. Such services might include mobility aids and adaptations to housing, mobility and other rehabilitation services for people with a visual impairment, interpreting services for deaf people who use British Sign Language

E. Housing Issues in Community Care

1. Introduction

While there are some housing issues which are specific to particular client groups, it may be useful to explore the whole picture of how housing issues affect those in need of care in the community, and the role housing providers can have in delivering flexible responses to community care needs.

Harrison and Haywood researched the extent to which community care plans and public health reports considered issues of housing need (the research predated the change from community care plans to health improvement plans). They found that housing issues were rarely mentioned, although there is extensive research to demonstrate that "worries about maintenance, cleaning and gardening are major issues for them"

In particular, Harrison and Haywood found that while homelessness and adaptations for disability were covered in most reports, there was little mention of problems arising from substandard housing. They conclude that:

"The words 'health' and 'housing' have come to have very narrow meanings ... 'Housing' is seen as the allocation, maintenance and management of stock in the public sector; 'health' has become restricted to the services provided by doctors and nurses"

and

"Non-housing professionals are not usually well-informed about the range of possible options for older people"

(Source: Harrison and Haywood, *Health Begins at Home: Planning at health-housing interface for older people*, Policy Press, 2000.)

This research may help to explain the emphasis in current government policy on partnerships and "joined up working" as in Health Action Zones and Care Trusts.

The Centre for Housing Policy at York University undertook a literature review which showed that "low-intensity support" services played a valuable role in maintaining people in independent living in the community. However, these were often

given a much lower profile than high-intensity services and crisis intervention. (Centre for Housing Policy, *Low Intensity Support Services: a Literature Review*, Policy Press, 2000.)

Low-intensity support includes:

- Housing and tenancy support
- Direct practical support including domestic help and good neighbour schemes
- Emotional/social support including befriending and homevisiting services
- Housing services and innovation in community care

2. Housing Services and Innovation in Community Care

Since the implementation of the NHSCCA, opportunities have arisen for housing agencies (particularly housing associations) to become involved in a range of services for people with community care needs.

Independent sector organisations such as housing associations have been able to develop innovative and flexible responses to community care needs. These have included:

- A range of sheltered housing, from traditional warden schemes to sheltered and very sheltered schemes where a high level of support is needed. Very sheltered or extra care housing can incorporate services provided by a range of health and social care agencies.
- New developments in residential care, where a scheme can
 combine elements of sheltered housing with the functions of
 a registered care home. Such a service might be laid out in
 individual flats but be staffed by care assistants who can
 provide all the services of a more conventional residential
 home.
- Many older people live in owner-occupied housing which is older and in poor condition. Care and repair schemes can help bring their homes up to a standard that enables them to continue living independently despite increasing frailty.

Example: Quilgars describes an inter-agency project in Yorkshire which aimed to provide permanent housing combined with low level support to people with mental health problems (Supporting People with Mental Health Problems in Ordinary Housing, Policy Press, 1998).

3. The Future Role of Housing in Community Care Lifetime Homes

The Joseph Rowntree Foundation has been working for some time on the concept of lifetime homes. These are homes which incorporate the features needed to enable people to continue living in the same home once they have developed a disability, This should reduce the needs for residential care. The table below sets out the standards for lifetime homes.

A Lifetime Home incorporates all the relevant standards listed below.

Access

- 1. Where car-parking is adjacent to the home, it should be capable of enlargement to attain 3.3 metres width.*
- 2. The distance from the car-parking space to the home should be kept to a minimum and should be level or gently sloping.*
- 3. The approach to all entrances should be level or gently sloping.* (Gradients for paths should be the same as for public buildings in the Building Regulations.)
- 4. All entrances should be illuminated*** and have level access over the threshold, * and the main entrance should be covered.
- 5. Where homes are reached by a lift, it should be wheelchair accessible.*

Inside the home

- 6. The width of the doorways and hallways should accord with the Access Committee for England's standards.*
- 7. There should be space for the turning of wheelchairs in kitchens, dining areas and sitting rooms and adequate circulation space for wheelchair users elsewhere.
- 8. The sitting room (or family room) should be at entrance level.*
- 9. In houses of two or more storeys, there should be space on the ground floor that could be used as a convenient bed space.
- 10. There should be a downstairs toilet** which should be wheelchair accessible, with drainage and service provision enabling a shower to be fitted at any time.
- 11. Walls in bathrooms and toilets should be capable of taking adaptations such as handrails.
- 12. The design should incorporate provision for a future stairlift* and a suitably identified space for potential installation of a house lift (through-the-floor lift) from the ground to the first floor, for example to a bedroom next to the bathroom.***
- 13. The bath/bedroom ceiling should be strong enough, or capable of being made strong enough, to support a hoist at a later date.***
 Within the bath/bedroom wall provision should be made for a future floor to ceiling door, to connect the two rooms by a hoist.

continued...

14. The bathroom layout should be designed to incorporate ease of access, probably from a side approach, to the bath and WC. The wash basins should also be accessible.***

Fixtures and fittings

- 15. Living room window glazing should begin at 800mm or lower, and windows should be easy to open/operate.***
- 16. Switches, sockets and service controls should be at a height usable by all (i.e. between 600mm and 1200mm from the floor).***

Notes

- *Designated as 'essential' in the Housing Corporation Scheme Development Standards.
- **Designated as 'essential' in the Housing Corporation Scheme Development Standards for five persons and above dwellings, and recommended in others.
- ***Designated as 'recommended' in the Housing Corporation Scheme Development Standards.

(Source: Joseph Rowntree Foundation, *Building Lifetime Homes*, 1997.)

The Foundation stresses that incorporating these standards in new build should not be expensive, especially when the anticipated savings in residential care costs are taken into account. Lifetime homes are designed so that people with moderate mobility difficulties can quite easily be accommodated in general needs housing. For people with more severe disability, adaptations should be relatively easy to make. Lifetime homes standards could also be included in modernisation schemes

Housing agencies also have a major role in regeneration activities which seek to promote the growth of more active communities and mutual aid.

Self Test 2	
1.	How would you define self-advocacy?
2.	How well are housing needs addressed in planning for health and community care?
3.	What type of person would benefit from lifetime homes?
Nov	v turn to the Answers at the end of the Block.

Answers

Self Test 1

- 1. NHSCCA 1990.
- 2. Under the Carers Act, carers have a right to an assessment of their own needs. Young carers also have rights under the Children Act to be considered as children in need.
- 3. The Local authority Social Services Department and the Health Authority.

Self Test 2

- 1. Self-advocacy is where the person with a learning disability represents their own views, with or without assistance from an enabler.
- 2. Harrison and Haywood found that housing issues were rarely mentioned in community care plans and public health reports.
- 3. Lifetime homes are for everyone. They are designed so that should people develop disability they will be able to stay in their own home, rather than being designed as "special needs" housing.

Appendix 1: Information for Carers from Hampshire County Council, taken from Hantswebwebsite

www.youngcarers.hants.org.uk

Information for Carers

Who is a carer?

A carer is anyone who provides a great deal of care for a relative or friend on a regular basis without payment. Carers can be any age and do not necessarily live in the same house as the person they care for.

This section gives you information that is specifically for you as a carer, but you should find that much of the other information in the Guide is helpful - such as the sections on equipment and gadgets, Social Services and the list of organisations that can provide help at home.

Looking after yourself

An assessment of your own needs

If you are a carer you have a right (under the Carers Act 1995) to ask a Social Services care manager to make an assessment of your own needs as well as of those of the person you look after. Ask for a separate 'carer's assessment'.

If you have an assessment it gives you a chance to find out about and ask for help that will make it easier to continue to look after your relative or friend. An assessment of your needs makes sure they are taken into account when help is arranged.

Getting a break

It is important that you have regular breaks from caring and time to yourself. The services that can provide this are often called 'respite care' by Social Services, and mean that the person you care for is looked after for anything from a few hours to a few weeks while you get a break.

Services that can help include day centres which provide activities and company for the person you look after and sitting services where someone comes to your home to spend time with your relative or friend while you have time to yourself.

Many residential homes offer informal day care, where someone can regularly spend a day with the residents, have meals with them and join in the normal activities. You can find details of homes near

you that offer this service in the Guide to Residential Care. Printed copies are available from Social Services offices or by phoning 0800 028 0888.

It is also possible to arrange short stays in a residential home either as a one off (perhaps to allow you to go on holiday) or on a regular basis. Social Services can advise you about this or you can use the Guide to Residential Care to find homes that can offer short stays. If you want to go away for a break and you are concerned that your relative or friend would be very disorientated if they went to stay in a residential home it is possible to get live-in help for a short period. Organisations that can provide this are listed in the 'help at home' section.

Talking things through

There may be times when you want to talk to someone who understands the pressures of being a carer, or want practical advice or support to help you cope. Social Services runs an evening and weekends helpline for carers that can provide a listening ear, helpful advice and practical help in an emergency.

- Carers Helpline (Hampshire & Portsmouth) 0845 722 1122 Mon-Fri 5pm-12.30am weekends and bank holidays 8.30am-12.30am
- Carers Support Line (Southampton): 023 8023 3344 Mon-Thurs 5pm-8.30am, at weekends from Fri 4.30pm-Mon 8.30am, and all day on bank holidays

At times of crisis or major change in your life you may want to talk things through with someone who is not directly involved someone who can listen and help you decide what you want to do. There are professional individuals (usually called counsellors) and groups who can help you, and some specialise in help in particular situations (for example, after the death of someone close). You can get details of local counsellors from your doctor or from your nearest Social Services office.

Putting your point of view Help and Support

Whenever you are dealing with any organisation you can ask someone to be with you at any discussion about what help or information you need. This can be a relative or friend or someone from another 'neutral' organisation. Ask at your local Citizens Advice Bureau for advice if you want to find someone other than a relative or friend to help you (see the Phone Book for addresses).

More information

The Carers Handbook is published by Hampshire Social Services and gives information that will help you ask the right questions to find the help and information you need. It supplements the Guide to Care at Home. The revised booklet is available free from September 2000 from Hampshire Social Services offices or by phoning 0800 028 0888.

Specialist support

- Carers National Association, Ruth Pitter House, 20-25 Glasshouse Yard London ECIA 4JT tel 020 7490 8818 CarersLine: tel 0808 808 7777 Mon-Fri 10am-12 noon 2-4pm website www.carersul.demon.co.uk
- Carers Together in Hampshire, Unit D6, The Premier Centre, Abbey Park Industrial Estate, Romsey S051 9AQ tel 01794 519495 website carers@tcp.com
- Carers Centres

Carers Centres offer contact with other carers, local information and support, and a chance to make your views known.

- Andover Carers Centre 01264 362600
- Eastleigh Carers Centre 023 8090 2404
- Fareham Carers Centre 01329 282929
- Gosport Carers Centre 023 9250 1592
- Romsey Carers Centre 01794 511234
- Winchester Carers Centre 01962 842034

There is now a Young Carers Web site, specially designed for young people and the professionals and volunteers working with them.

Appendix 2: Young Carers Information

This site comes Highly Commended!!

On 29th November 2000, the Young Carers Website received an award as 'Highly Commended' in the annual national Community Care awards for new and innovative service to carers. On the same day, the site was chosen by the Department of the Environment, Transport and the Regions as an example of good practice in providing information and access to help young people in the rural areas of the south of England.

You can find information here on what may be available to help you and who the different people you come into contact with are.

You can join the Forum to contact other young people in the same situation, in confidence. Once you've registered you can chat with other Young Carers.

You will also find lots of links and information about what is happening in the county and elsewhere on a whole range of subjects (you can suggest new links that you have found as well). There are also links to fun sites, music, sport, games and much more!!

There is also information for adults who know a young carer.

And information for professionals and volunteers working with young carers.

This site is run by young carers who have come together to set out what they want to see and use - if you have any comments you want to make or new things you want to add to the site please use the feedback form.

If you want to help decide what is on this site please use the feedback form and join in with the others when we meet to decide what to do next.

© Copyright Hampshire Social Services and the young carers of Hampshire.