Avon and Wiltshire NHS
Mental Health Partnership NHS Trust

Carers Pack

Bristol Older People's Mental Health Service

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Contents

Introduction

This booklet aims to provide a short practical, straightforward guide to the first questions that many carers have asked us as a department in the past. It is recognised that these days, there are many sources of information such as television, books and the internet which provide information on different health conditions. This pack aims to answer some initial questions and provide you with some contact details if you want to find out more.

This pack is made up of information from many sources including "An information pack for relatives and friends who care for people with mental health problems", published by Avon and Wiltshire Mental Health Partnership available on wards for Adults and from the Community Mental Health Teams for Adults. Relevant information from a similar pack produced by the Southampton Mental Health Trust has also been included.
Another useful resource has been the booklet "Who Cares", which is a comprehensive guide for people caring for older adults with dementia and is available from the Department of Health. It can be ordered by telephoning 08701 555 455, or e mailing dh@prolog.uk.com for a free copy.

We are committed as a team to provide good information to patients and carers, and we hope this pack aids that process.

If you have any comments or questions that you would like to see added to this pack then please call:

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Carers Rights

Who is a carer?

A carer is someone who looks after a relative or friend, who, due to disability, confusion, frailty or illness, cannot manage alone. Anyone who is providing unpaid support and care for someone who could not manage without it, is a carer. Carers are people of all ages, all ethnic groups and all religions. However, many people do not realise that they are a carer; this means that they can miss out on the support, services and benefits available for them.

Carers rights and carers assessments

The following rights apply to anyone providing or intending to provide regular and substantial care to a sick or disabled person. Rights under the Carers and Disabled Children Act 2001:

- Right to an Assessment of Carers' Needs – carers may have a right to an assessment of their needs as a carer, even if the person they care for chooses not to be assessed.
- Right to carers' services – local authorities now have the power to provide services to carers to meet their needs. These services cannot be intimate services for the disabled person; in other words, they cannot involve washing, bathing, dressing, feeding, etc.
- Direct Payments – the power for local authorities to provide Direct Payments to carers for their own services, giving them far more choice and control over their lives.

Most people who develop dementia and mild mental health problems will be cared for by their family doctor and Adult Community Care services. This pack is aimed at helping people find their way through the system. When more severe symptoms occur you will be referred to the Community Mental Health Team for Older Adults (CMHT). If the person you care for is referred to the CMHT a key part of the initial assessment will be to see if they meet the Mental Health eligibility criteria. This will be explained to you in detail should the need arise.

Looking after yourself as a carer

In many cases it is down to the carers to maintain the daily functioning of the

person with dementia. The level and degree varies with each person but if there is something that is almost always forgotten, if you were not there, who would do the caring duties?

All situations are different, but the common trend seems to be that the responsibility for the main caring tasks falls to one person.

- **Feelings**

Being a caregiver can be overwhelming. There are a number of feelings commonly experienced by carers such as guilt, embarrassment, helplessness and anger. The list is not exhaustive. The stress of caring can, at times, take quite a toll on the carer's overall wellbeing. However, caring can also produce positive feelings such as pride and enjoyment and mixed feelings are by no means uncommon.

- **Looking after yourself**

It's all too easy to ignore your own needs when caring for someone with dementia and forget that you matter too! Allow family and friends to be involved and try not to turn away help; these offers are usually genuine and can greatly help you and the person you care for. See to your own health (sleep, diet, exercise, breaks etc). Ensure that you have time for yourself and do not feel guilty about this protected time.

- **Moving and handling**

There are some general pieces of guidance to be passed on when considering moving and handling of someone who may have difficulty in walking or rising from a bed or a chair. Keeping the person mobile will encourage them to do as many things for themselves as they can possibly manage. Cooperation is required. You may have to become more ingenious in your communication to persuade the person to remain active. It is important to highlight safety as a consideration and never attempt to 'carry' someone on your own. There are aids and adaptations available to help in and around the home (chair risers, walking aids etc). If you encounter problems, you can contact a Physiotherapist or Occupational Therapist via your GP or if the person you care for is seen by the specialist Mental Health Services, these issues can be raised with your care coordinator.

Staying Healthy

Both you and the person with dementia will want to remain as healthy as

possible. The better you both feel, the more you enjoy life. Try to arrange annual general health checks with your GP. Medication may be an issue when a person gets older and will need monitoring by the carer for signs of discomfort. Otherwise take the health promotion of good mobility, diet, regular dental and eye checks, low alcohol intake, cut down on smoking, be aware of any hearing deficits and keep an eye on any foot problems.

The diagnosis: The main mental illnesses

The following summaries of the most common mental illnesses provide a brief insight into the main features of each one and are not intended as a comprehensive source of information. For more details on a particular illness, please speak with a professional. Further information is available from many places on the internet; MIND has a wide range of information at www.mind.org.uk
(see Useful Contacts).

Anxiety, panic or phobias

Anxiety disorders are quite common, affecting about 5% of the population at any one time but many people do not seek help. Anxiety and fear are normal human feelings which are considered essential to our survival. However, normal anxiety becomes severe when the symptoms are so intense they stop people from coping with day-to-day activities. Extreme fears, sometimes called phobias, are intense and disabling fears of specific things or situations.

People who suffer from intense anxiety find it difficult to concentrate, tend to sleep badly, get tired easily and are 'on edge' most or all of the time. The body shows the effects of anxiety by increased heart rates, tension in muscles, inability to relax, sweating, over breathing, dizziness, faintness and bowel disturbance. Sudden unexpected surges of anxiety are called panic attacks. Someone who has a phobia has symptoms of intense anxiety or panic but only in particular situations. Phobias tend to lead to avoidance of the things which are feared.
Talking about the problem to trusted friends and relatives often helps and may give a sense of perspective. Most of us tend to avoid stressful situations, but in the case of anxiety disorders it tends to make the situation worse due to the fear it induces. Specific treatments may sometimes be required such as Cognitive Behaviour Therapy (CBT) or Anxiety Management. These can help people to recognise, understand and manage their anxiety. Learning to relax with advice from professionals or by using tape cassettes or books can help to bring tensions and anxieties under control. Medication such as tranquillisers or anti-depressants may be used to help ease anxiety during the day or help sleep at night. For further information: contact the National Phobic Society (see Useful Contacts).

Dementia

Sometimes, confusion can be caused by underlying physical disorders which are treatable. Some other mental health problems, such as depression or anxiety, can cause temporary changes to concentration and memory which improve as the mood disorder lifts. These conditions may mimic a dementia and for these reasons it is important to get a proper diagnosis.

'Dementia' refers to a range of neurological conditions affecting the brain.

The most common dementias are 'Alzheimer's disease', 'Vascular dementia' and 'Lewy Body disease'. It is not always possible to be sure which form of dementia a person has, and quite often a person will have signs of more than one type; this is often called 'mixed dementia'. Rarer types of dementia include Pick's Disease, Huntingdon's Disease and Creutzfeldt-Jakob disease (CJD).

Typical signs of dementia include loss of memory, confusion, problems with speech and understanding, and changes in personality and behaviour. The disease develops over time, although some changes, such as aggression or agitation, can ease as the disease develops. Some people will become severely disabled while others will be able to manage for themselves with minimal help, sometimes for many years.

Caring for somebody who has dementia can be challenging in a number of ways; for example dealing with unusual behaviours, making financial arrangements, maintaining good health and quality of life. The Alzheimers Society has useful information about dementia at www.alzheimers.org.uk (See the links on the left of the page under 'About Dementia').

If you do not have access to the internet, please ask your family doctor, librarian or care co-ordinator for assistance.

Medical treatment of Dementia.

There is as yet no cure for Dementia. However, drug treatments have been developed that can temporarily slow down the progression of symptoms in some people. For more information on the drugs available to treat Alzheimer's disease, the Alzheimer's Society free information sheet 407, which gives an overview of the medications available, may be helpful, (see useful contacts). Alternatively, talk to some one in the Community Mental

Health Team for Older People or your GP. Sometimes, medication to calm someone is useful, but it is important to get the right dose, as some people can be very sensitive to such drugs.

Dementia may also make a person depressed, possibly requiring the use of anti-depressant medication.

It's also very important to treat other illnesses, like chest or urine infections, quickly. These can make the symptoms of dementia dramatically worse and you should see your GP if there is a sudden, even if minor, change.

Depression

Anyone can get depressed; about 1 person in 20 will suffer from severe depression at some stage. When people are severely depressed, they feel that life has little to offer them and that things will never get better. This low mood is more than being fed up or unhappy: it is persistent and can coincide with disturbed sleep, low appetite and libido, feelings of hopelessness, poor concentration and memory, thoughts of suicide and can severely affect daily functioning.

People can become depressed as a result of external events (e.g. the death of someone close, loss of job, etc.). In such circumstances it is normal to feel low in mood, tearful, and unable to cope. This is not called depression unless it is particularly severe or else the person remains 'stuck' for a long time. Excessive stress is a common cause of depression, and the caring role can put some people at risk of becoming depressed. For other people who become depressed , there is no obvious cause or trigger.

Depression can be treated and should not be ignored, so if you think you or someone close may be depressed, do discuss this with your family doctor or care coordinator.

Treatment

Anti-depressant medication is a common treatment for depression. They work on chemicals in the brain to help improve the mood. They are most effective when used in conjunction with other forms of help, such as talking therapy, exercise or practical assistance to reduce the burden of stress. For further information contact the Depression Alliance - www.depressionalliance.org

Schizophrenia

Schizophrenia is a diagnosis used for people who have psychosis plus other factors. In Psychosis, thinking becomes severely distorted, making it hard for people to distinguish between shared reality and what is imagined (hallucinations or delusions). When severe, this can lead to immense panic, anger, depression, elation or over activity, perhaps punctuated by periods of withdrawal.

Psychosis is relatively common, with approximately one in one hundred people experiencing an episode of psychosis at some time during their lives. In older people it may indicate a physical problem, or it may be associated with dementia, severe depression or late onset schizophrenia.

Obsessional Compulsive Disorder (OCD)

OCD is a disorder characterised by obsessions and/or compulsions. OCD is common, affecting approximately 1 or 2 in 100 people. It usually appears in childhood or adolescence but continues into adulthood. It is an exaggeration of normal thoughts and actions which happen in nearly everyone. Most people find that from time to time they have worrying thoughts which they cannot get out of their head or they carry out repetitive actions which are not really necessary. Obsessions are recurrent, persistent thoughts or ideas that the person may feel are senseless but is unable to ignore them.

Compulsions are repetitive, ritualistic behaviour which the person feels driven to perform. Obsessions and compulsions in OCD can cause a lot of distress to the individual and their family. They can be very time consuming, interfering with people's daily lives.

Treatment

Cognitive Behaviour Therapy and other forms of psychological/talking therapy have been shown to be very helpful in treating OCD. It involves learning to gradually manage the situations which would normally provoke compulsive actions. Sufferers may learn skills to help them resist the compulsions and to tolerate the discomfort they experience as a result which gradually lessens with time. Therapy also aims to change the way sufferers think about the situations associated with their OCD.

Certain anti-depressant medications can also be very helpful, particularly when used in conjunction with therapy.

Sufferers from more mild forms of OCD can benefit from self-help techniques, either individually or within a group. For further information: contact OCD Action at www.ocdaction.org.uk

Eating Disorders

Anorexia Nervosa and Bulimia Nervosa are the two psychiatric diagnoses for eating disorders. In Anorexia Nervosa, people eat too little, and deliberately lose weight because of a distorted body image. In Bulimia Nervosa, people tend to eat chaotically, although they may make themselves vomit or take laxatives to reduce the weight gain effects of over-eating. Both tend to occur more in younger people.

Anorexia itself (as opposed to Anorexia Nervosa) simply means decreased appetite - and can occur for lots of reasons. For example, after a healthy person eats a meal the appetite decreases - this is called post-prandial anorexia. Other causes of loss of appetite include bereavement, stress, depression, and a range of physical illnesses. While Anorexia Nervosa is not believed to be very common in older people, loss of appetite is felt to be quite common. Weight loss associated with loss of appetite can bring serious health problems, and it is important to discuss this with your family Doctor or a member of the Mental Health Team.

Bi-polar disorder (Manic Depression)

This is a mental health problem that is characterised by periods of deep depression and of extremely excited behaviour known as "mania" or "hypo-mania". About one in a hundred people are diagnosed as having manic depression. Around 15 per cent of people who have a first episode of manic depression never experience another one.

Managing Finance and Benefits

The Benefits and Social Security system can be perceived by many as being complex, time consuming, frustrating and generally not worth the hassle. Other views are that you are taking handouts from the state and people feel uncomfortable accepting them.

Please remember these benefits have been set up to acknowledge that your caring role, no matter why you do it, is ultimately unpaid.

If you have not already done so, we recommend that you at least review your current financial situation sooner rather than later. Here is a summary of the main avenues that you may wish to pursue as a carer. It is by no means a complete overview but there will be further information and support available from your local Social Services office, or department of Work and Pensions (DWP).

Benefits

An important step following a diagnosis is considering how you will manage financial arrangements in the future. Undertaking a caring role for someone with dementia may mean that you are entitled to a number of benefits or the person you care for may be eligible for benefit.

What benefits are available?
There are many benefits available for older people such as:

- Help for people on a low income
- Retirement pensions and bereavement benefits
- Benefits for people with disabilities and their carers
- Financial assistance and reductions

There are some benefits that you can consider applying for NOW if you have not done so already.

Attendance Allowance

The person being cared for must be over 65 years (if not, apply for Disability Living Allowance). It is not means tested. It is provided for those who need help and supervision with daily life activities (what

could the person do if the carer was not present). The forms take about an hour to complete but it is worth around £49. 30p. - £73. 60p. per week.

Disability Living Allowance

The person being cared for is under 65. The same rules apply as for Attendance Allowance.

Carer's Allowance

Carers may be eligible, if under or over 65 years of age, and unable to work full time because of caring duties. The person being cared for must be receiving Attendance Allowance or Disability Living Allowance for the carer to qualify. In some circumstances if you are over 65 years of age, and not intending to work, it may still be to your advantage to apply for Carer's Allowance.

Council Tax

Households with a person with a diagnosis of Dementia may be entitled to a reduction in Council Tax contributions (25% if living with someone else, 100 per cent if living alone). However this does not apply if there are more than 2 adults living at the property. Ask at your local council office.

Legal Arrangements and Financial Issues

It is important to plan ahead, and there are other important financial and legal considerations you may need to consider such as:

Legal issues concerned with managing the financial affairs of the person with dementia.

Mental Capacity

This is basically the ability to understand and retain information adequately, enabling competent decisions to be made. It must be remembered that the law assumes all adults 'are competent' in communicating and making decisions. The problem with dementia is that the decision-making processes may fluctuate or be impaired. (The new Mental Capacity Act came into operation in October 2007).

Agency

A person who receives a benefit or a pension may nominate someone – called an 'agent' – to collect the money for them, but not to spend it.

Appointee

If someone who is entitled to a Social Security benefit or allowance is unable to act for themselves (because of dementia) a representative of the Secretary of State for Social Security – usually the benefit supervisor in the local Benefits Agency (Social Security office) – may, on receiving the application, appoint someone else to exercise the claimant's right to make claims for and to receive benefits, and to spend them on behalf of the claimant. It is accepted policy that a close relative who lives with or frequently visits the claimant is the most suitable person to act. There are guidelines and powers demanded of an appointee.

Third Party Mandate

This can be used by someone who is mentally capable but is unable to carry out a particular transaction – for example, the person may be physically unable to visit the bank, and may need someone to do this on their behalf.

A Power of Attorney

This is a legal document that authorises one or more people to handle another person's financial affairs (including property, shares, money, etc.), either generally or in relation to specific items. The donor can revoke the power at any time. In addition the Power of Attorney becomes invalid if the person can no longer understand Power of Attorney and/or manage their affairs.

Enduring Power of Attorney (EPA)

This is a legal document which authorises one or more people to handle another person's financial affairs (including property, shares, money etc) and will continue even if the person no longer has mental capacity, provided that it is registered with the Office of the Public Guardian (previously known as Public Guardianship Office). The donor may cancel or revoke an EPA at any time provided that he or she has the mental capacity to do so. But an EPA cannot be cancelled or revoked without the Court's consent once it has been registered. From 1st October 2007 no new Enduring Powers of Attorney can be made. If they are already made

and dated prior to last October 2007, they can still be registered.

The Lasting Power of Attorney

This new Lasting Power of Attorney is introduced by the Mental Capacity Act 2005. It enables a competent person to hand over decision making to other people. There are two kinds. The first one is a Property and Affairs Lasting Power of Attorney. The second is called a Personal Welfare Lasting Power of Attorney and this one relates to care and treatment making decisions. Both operate in a similar way to the Enduring Power of Attorney.

The donor may cancel or revoke a Lasting Power of Attorney at any time provided that he or she has the mental capacity to do so. But a Lasting Power of Attorney cannot be cancelled or revoked without the Courts' consent once it has been registered with the Office of the Public Guardian.

Deputyship

A Carer can apply to the Court of Record once a person no longer has the capacity to manage their finances. The Court has the power to either issue a Court Order or if there is a need for ongoing decisions, an individual may need to be appointed as a Deputy. The Court will make a decision regarding the powers and scope of the Deputy.

The Court of Protection

The Court of Protection is now a Court of Record. It exists to protect the people who suffer from lack of capacity. This Court deals with all matters relating to mental incapacity, including the Property and Financial affairs and Personal Welfare of people who lack capacity. The Office is also responsible for Powers of Attorney and the control of Deputies.

Important Note: We would advise carers to seek appropriate advice such as a solicitor in dealing with the above financial matters.

Useful Contacts

BRISTOL Community Mental Health Teams for Older People – "Single Points of Entry":
Bristol South West and South East (Tel 0117 919 5800);
Bristol East (Tel 0117 301 2345);
Bristol North and North West (Tel 0117 323 6238).
In very complex situations, these teams can offer an assessment of need, treatment and support.

NHS Direct
Telephone 0845 4647.
www.nhsdirect.nhs.uk
Provides health advice and information from qualified nurses 24 hours a day.

Adult Community Care
Care Direct Tel 0117 9222 700 (Fax 0117 903 6688) (out side of office hours Telephone 01454 615 165).
Provides advice, information and help for service users and their carers. If your first language is not spoken English, a telephone interpreting service can be arranged.

Rethink Project (St. Paul's Settlement)
Telephone Carers Line 0117 9031803
www.rethink.org
Provides information and support for carers.

Bristol City Council
Telephone 0117 922 2000 (main switchboard).

Carer's U.K. (Headquarters)
Telephone 0808 808 7777
www.carersuk.org

CITA (Council of Involuntary Tranquilliser Addiction) Telephone 0151 949 0102
An information and help line.

Depression Alliance
Telephone 020 7633 9929.
Provides information, support and understanding for people who suffer with depression and for relatives who want to help.

Hearing Voices Network – Telephone 0161 228 3896.

Mind, National Association for Mental Health
Telephone 020 8519 2122 (head office)
Telephone 0345 660163 (information line).
www.mind.org.uk
A national organisation that aims to work for a better life for people diagnosed, labelled or treated as mentally ill.

National Phobic Society
Telephone 0161 881 1937. A national membership organisation providing help and advice for sufferers, their carers and their families.

Obsessive Action
Telephone 020 7226 4000 –
A national organisation that offers advice on Obsessive Compulsive Disorder.

Saneline, National Helpline
Telephone 0845 678000 (12.00 noon to 2.00am, 7 days a week).
Provides a national out-of-hours telephone help line for anyone coping with mental illness – individuals, carers, concerned relatives or friends.

Dementia Focus

Alzheimer's Society (Bristol Branch)
Telephone 0117 961 0693
(National Help Line Telephone 0207 306 0804)
www.alzheimers.org.uk
Provides advice, information, support in a crisis, day care, self help and support group for people with dementia and their carers.
Alzheimer's Society Gay and Lesbian Carer's Support Scheme Help Line Telephone 0845 300 0336.

Dementia Care Trust (Bristol Branch & H.Q.)

Telephone 0117 952 5325.
Provides information, respite, sitting service and other services for people with dementia and their carers.

Functional Mental Health Focus

Bi Polar Association (Bristol)
Provides a monthly self help group for people with manic depression and those caring for them and supporting them. Mobile Telephone Number 0845 434 9776. For further information E mail – groups@mdf.org.uk

No Panic
Telephone 0195 259 0005.
(Help Line Telephone 0800 808 0545)
Provides a help line, information and support group to people with anxiety disorders.

Depression Alliance
Telephone 020 7633 9929
Provides information and support for people who suffer with depression and for relatives who want to help.

Hearing Voices Network
Telephone 0161 228 3896
Provides support for people and their carers.

Carers Focus

Black Carer's Project
Telephone 0117 914 4492 Fax 0T117 914 4491
E-mail admin@blackcarersproject.co.uk
www.blackcarersproject.co.uk
Provides training , support and advocacy , information and advice for adults, older people and carers from black and other minority ethnic communities. Also a “sitting service” for African/African Caribbean communities as well as providing support and activities for young black carers through the Young Black Carers Project. (operates Monday to Friday 9.30am to 4.30pm).

Princess Royal Trust Carers Centre
Telephone Carers Line 0117 965 2200 (operates Monday to Saturday 10.00am to 1.00pm) Provides help, support and advice to carers across the

city.
(National Help Line Telephone 0345 573 369)
Fax 0117 965 5847 E mail www.carers.org

Black and Other Minority Ethnic Groups Focus

Black Carer's Project - see above under "Carers Focus"

Bristol & Avon's Chinese Women's Group
Telephone 0117 935 8035 Fax 0117 955 3330
Provides information, support and advice to meet health and social care needs of men and women, for example, extra care housing, day centre, activities for carers and a "sitting service".

Dhek Bhal
Telephone 0117 955 6971
Provides information, support and advice to meet the social care needs of men and women, for example, by providing Day Centre, Sitting Service and Carers Support Group.

St. Paul's Advice Centre
Telephone 0117 939 7782
Provides general support and advice on a wide range of issues. Benefits Advice by appointment. (open 10am to 12 mid-day Monday to Friday).

Practical Support and Transport Focus

Age Concern (Bristol)
Telephone 0117 922 5353 (National Help Line 0800 009 966
www.ageconcern.org.uk
Provides advice, information, and services for older adults and carers, for example, a befriending service and weekly telephone support service.

Crossroads
Telephone 0117 983 9955 (North Bristol)
Telephone 0117 923 1125 (South Bristol)
Provides general and emotional support to assist people to live independently in their homes and a "sitting service".

Shopmobility
Telephone 0117 922 6342

Bristol-Dial-Ride
Telephone 0117 939 5525
Provides door-to-door transport for anyone with mobility impairment and covers most parts of the city.

Blue Parking Badge for disabled people
Telephone 0117 922 2997 (or call the city council's switchboard).

Legal and Financial Support Focus

Avon and Bristol Law Centre
Telephone 0117 924 8662 (general advice).
Telephone 0117 916 7722 (benefits advice).

Bristol Debt Advice Centre
Telephone 0117 954 3990

Citizens Advice Bureau
Telephone 0117 921 1664

East Bristol Advice Centre
Telephone 0117 941 5892

North Bristol Advice Centre
Telephone 0117 951 5751

South Bristol Advice Services
Telephone 0117 985 1122

A check list of questions

Families and friends of a person who is being supported in the community are often anxious and exhausted trying to juggle the demands of their own busy lifestyle with meeting the needs of the cared for person. Community Mental Health Teams and Psychiatrists are also usually very busy and so it is a good idea to prepare a list of the things you need to know, ready, before you have a meeting with any of the team involved in your relative's care. This check-list is designed to help you do this. These questions have been included as a framework for you to use; you may not find them all helpful, and there may be others that we have not thought of.

This assumes that your relative/friend is happy for the member of the team to discuss these issues with you. However, if your relative/friend is unwilling for information to be shared there will be a problem with confidentiality. It is probably best to work through this issue prior to any meetings so that you are aware of where you stand.

About the diagnosis

- What illness does my relative/friend have?
- What symptoms/signs suggest this?
- What is known about the causes of the illness?
- What is likely to happen in the future? Will it get better or worse?
- Where can we get more information about this disorder?
- If there is no diagnosis yet what are the possibilities?
- How long will it be before there is a diagnosis?
- Who will provide me with the advice and support I need to deal with the behaviour/symptoms in the meantime?
- Can I have information about the diagnosis in writing?
- Can I, and the person I care for, be seen together to discuss the diagnosis and/or prognosis?

About the assessment

- What tests have been done?
- Will any more tests be needed?
- What are the results of the tests? How will these be acted upon?
- Have culture and background been considered?

About care and treatment

- What are the aims of the care and treatment?
- What part will the care co-ordinator play in my relative's care?
- Who else will be involved in the treatment?
- How often will you see your relative?
- What is your plan for treatment? How long will it last?
- Would psychological therapy (for example talking, art or music therapy) be helpful? If so, is it available on the NHS locally?

Medication

- What medication is to be used?
- What should the benefits of this medication be in the long term and the short term?
- What are the possible side effects of this medication in the long and short term?
- Why have you chosen this particular drug?
- Will it be necessary to take it for life?
- Are there any other drugs that could be used if this one does not work?
- What signs/symptoms might mean that the drug should be changed?
- What will happen if he/she stops taking the medication?
- Do you have any written information about this medication?

Care Programme Approach (CPA)

- Would you explain how the CPA will be used to help our relative/friend?
- When will there be a CPA meeting and will we be invited to it?

The family and the treatment

- Will the family/friend be involved in discussions concerning the treatment of our relative's problems?
- What can we do to help?
- Are there any local self-help groups?
- How should we respond to our relative's problems?

Getting help

- Who do we contact if we are worried about something?
- How can we get in touch with you?
- Whom do we contact in an emergency?
- How can we get a second opinion?

Hospital Treatment

- What happens if our relative/friend refuses admission?
- How long is he/she likely to need stay in?
- What arrangements will need to be in place in order for our relative/friend to leave hospital?
- Can arrangements for Benefits to be paid immediately on discharge be made, so financial security/housing does not become a problem?
- Who will inform utilities etc. that our relative/friend is admitted/discharged so that there is no danger of non-payment summons being incurred?
- If it is not appropriate for our relative/friend to return home, what other options are available in our area?
- Who can advise us about this?

Social care options

- Who do we contact regarding home care support in the home?
- How do we access Community Meals?
- What provision for Day Care is available in our area?
- Is the person I care for eligible for Respite Care?
- Who would we contact to discuss the implications of a Permanent Residential Care Placement?
- Where can I find out more regarding Direct Payments?

Understanding the Jargon

Professionals sometimes use terms and abbreviations which are unfamiliar to the lay person. However, if someone is speaking to you and using abbreviations or unknown phrases that you do not understand you can always ask them to explain what they mean. Don't feel that you will look foolish or ignorant; people often forget that not everybody uses the same language on a daily basis. Below is a list of some of the more common terms used.

Approved Social Worker (ASW)

Each Local Authority (Council) has a responsibility to provide sufficient numbers of social workers specifically trained and approved by the Local Authority under the Mental Health Act 1983. Their role is to assess people for hospital admission and, if they consider there is no alternative, to authorise admission and make the necessary arrangements. This is a specialist role and is different from the usual role of social workers. Most social workers are not ASWs.

Assessment and Review Coordinator (ARC)

Help people to regain their confidence and independence. They provide practical help with: budgeting, personal care and day-to-day living. They also offer emotional support, listen to people and help them manage their stress or anxiety and build up self-esteem and confidence.

Care Co-ordinator (or maybe Key Worker)

This is the member of the team who will co-ordinate the Care Plan and act as the link/contact for the Service User, Carer/s and other team members.

Care Programme Approach (CPA)

The Care Programme Approach is an approach used by the specialist mental health service. It is the process by which an individual's health and social care needs are assessed, care and support planned, delivered, and reviewed. This will be further explained to you if you come into our service.

Clinical Psychologist

Someone who can use psychological knowledge and techniques to help in understanding and treating mental health problems.

Community Mental Health Team (CMHT)

The local providers of NHS mental health services. These teams include Psychiatrists, Clinical Psychologists, Community Psychiatric Nurses, Social Workers, Occupational Therapists, Physiotherapists, and Assessment and Review Coordinators, who work closely together in assessing and developing a care plan to meet the needs of the person using the service.

Community Psychiatric Nurse (CPN) or Community Mental Health Nurse

A qualified mental health nurse who assesses and plans care. Often also acts as Care Coordinator (see above).

Continuing Health Care Funding

This can be considered for people with high levels of need. Leaflets and further advice are available from the Communications Team, Gloucestershire and Wiltshire Strategic Health Authority – Telephone 01249 858 660.

Direct Payments

If you or the person you care for have had an assessment and it has been agreed you can have help, you may be eligible to organise and buy the care you need yourself using Direct Payments. For further information discuss with your Social Worker or contact Wecil Ltd, The Vassal Centre, Gill Avenue, Fishponds, Bristol, BS 16 2QQ. Telephone 0117 903 8900 (Voice and minicom).

Home Care

Provide help with personal care and some household tasks. There is usually a charge for this service.

Meals Service ('Mobile meals', 'meals on wheels')

Delivers lunch and/or tea meals to the service user.

Mental Health Act (Detention under) & “Sections”

The legal power to detain someone in hospital against their will is used only when a person presents a significant risk to themselves or others, and refuses to go into hospital voluntarily. If this is likely to apply to a person whom you care for, then the meaning and application of the Mental Health

Act will be fully discussed with you.

Occupational Therapist (OT)

Occupational Therapists are trained to work with people to help them to improve their ability to cope with daily living as independently as possible. They can improve coping strategies as well as helping to encourage participation in recreational, educational and vocational activities.

Physiotherapist

Physiotherapy can help maintain or improve mobility problems in order to achieve independence and improve quality of life. It can also be useful in treating anxiety, depression and other mental health problems. Problems may range from falls, poor balance, general mobility problems, to pain and arthritis.

Psychiatrist

A medical doctor who has trained and specialised in psychiatry – the branch of medicine concerned with mental health, diagnosis, treatment and care. The consultant psychiatrist is the senior psychiatrist in a team.

Respite Care

When someone else takes on the caring for a period of time it is called respite care. Various organisations provide respite care. It can mean:

- someone coming to your home for a few hours to allow you to go out or get on with something other than caring.
- day care
- time limited residential care (perhaps for one or two weeks)

There are normally charges for this although it may be possible to get help with charges.

RMO (Responsible Medical Officer)

This term describes a doctor who is attached to the hospital Mental Health Team for Older Adults.

Social Worker

The social worker assesses, plans and organises care packages. They are experts in social care options.

Voluntary Organisations

Bodies governed by unpaid members, registered as charities with some paid members of staff. These are some that are specifically helpful for people experiencing mental health problems for example:

Dementia Care Trust	Alzheimer's Society
Age Concern	Mind
Samaritans	Saneline

(For more details see Useful Contacts).

Some Jargon used in Treatment options

Acetylcholinesterase (AChE) inhibitors

This is a type of medicine which can help some people with dementia. They do not change the course of the disease, but can for a period reduce the signs of dementia. A specialist Doctor is needed to decide which cases they are likely to be suitable for.

Atypical Anti-psychotic Medication

These are fairly recently introduced forms of medication to treat psychosis. Some of the more frequently prescribed are Amisulperide, Olanzapine and Risperidone, because they are thought to cause fewer side effects.

Anti-Depressants

Medicine used to help someone feel less depressed. These typically take several days to have an effect.

Depot Injections

Long acting medication sometimes used where people are unable or unwilling to take tablets regularly.

Electro-Convulsive Therapy (ECT)

This treatment is very rarely used nowadays, but, if it is considered necessary the doctor will discuss this with you in more detail.