



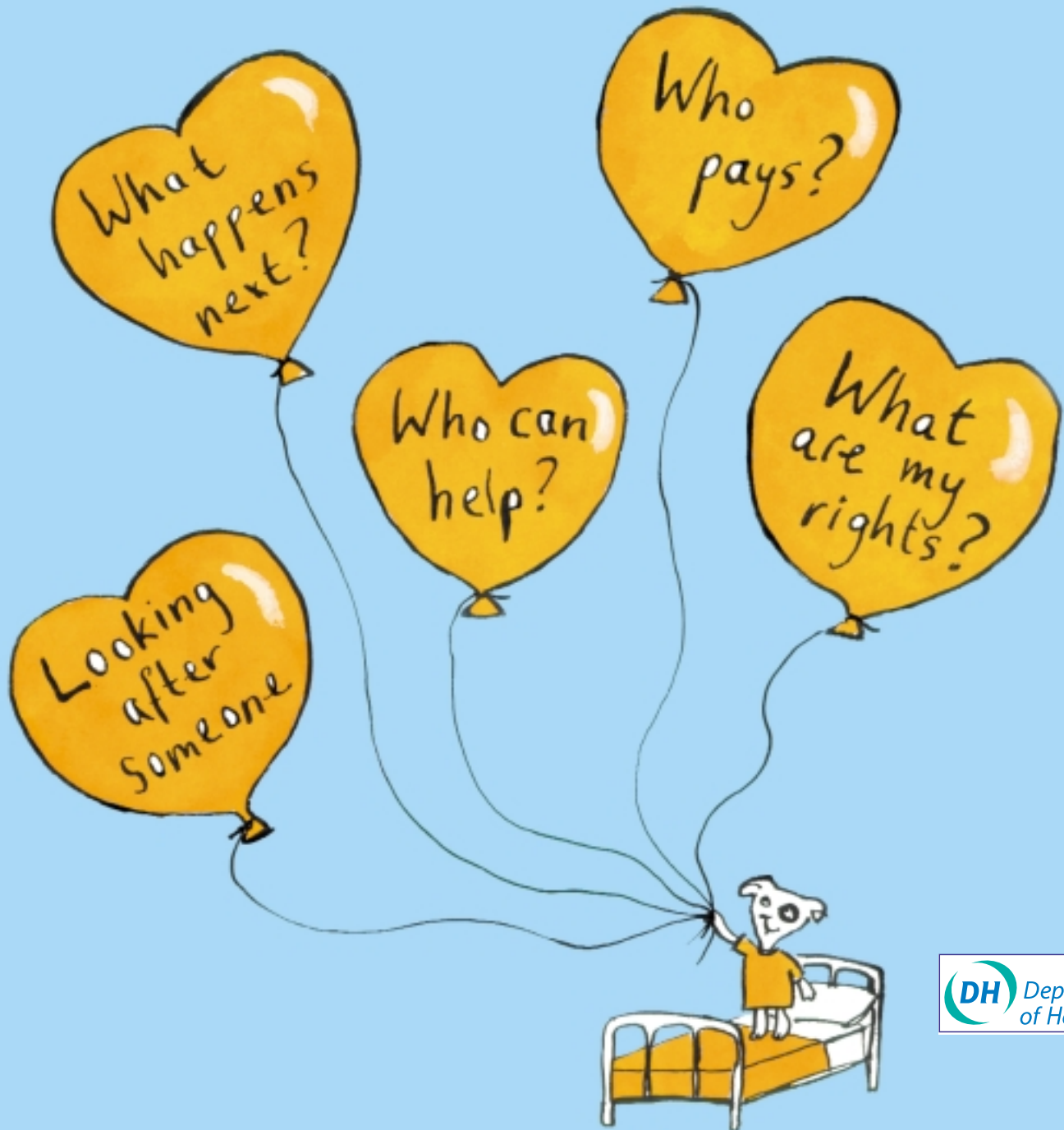
**caring
matters**

*The right advice
at the right time*

Where to turn!

A CARING MATTERS GUIDE

April 2002



www.caring-matters.org.uk

Please leave this copy here so that it can help others



Introduction

Do you need help, or help someone with:
 bathing, dressing, toileting,
 preparing meals, housework,
 handling money, standing up,
 walking, or climbing stairs?

Do you, or the person you care for, need help because of an injury, disability, old age, or because of a long illness that may not get better?

If the answer to these two questions is “yes”, then your care situation is known as long term care.

Long term care can be provided in your own home, sheltered housing, in a residential care or nursing home, or in hospital. Friends, family, voluntary or private organisations, social services, and health agencies may arrange or provide care.

Organisations providing long term care have limited time and resources. When you are aware of what services are available, who to ask for services, and when to ask, it will be easier to get the help that you need.

This guide describes how to help people who cannot care for themselves because of illness or disability. It also describes what should happen when you need help planning care at home, or moving away from home to receive care.

Knowing what to expect can help you feel confident and make the best care decisions.

Caring Matters can help you to get the right information at the right time.

Visit our web site for up-to-date information
www.caring-matters.org.uk

We are very grateful to the Department of Health, Westminster Health Care, and Alba Reprographics & Design for supporting our *Where to Turn! A Caring Matters Guide*.

Contents

Page

Foreword from Lord Morris of Manchester	3
Need help after leaving hospital?	4
Who decides what help we need?	4
What to expect from a needs assessment	5
Going home from the hospital	5
Help at home	6
Help with personal care and cleaning	6
Home care services	6
Equipment to help with living at home	7
What is an alarm scheme?	7
Selecting home help checklist	7
Support for Carers	9
Are you looking after someone?	9
Young carers	10
How do I write the care plan?	11
Caring for the Carer	12
Can others help with caring?	12
Taking a break from caring	12
Caring from a distance	13
Charging matters	14
Who pays for help at home?	14
What is a charging policy?	14
What are eligibility criteria?	15
What is continuing NHS care?	15
Am I eligible for free continuing care?	15
Direct payments	8
Care homes	15
Considering moving into a care home?	15
Can I choose my own care home?	16
Who pays for my stay in a care home?	17
Can I keep my home?	17
Can I give my home away as a gift?	18
What happens when my partner needs care?	18
Legal matters	18
What does it mean to be mentally incapable?	18
Protecting people from abuse and exploitation	19
Protecting a vulnerable person's money	19
Appointees, receivers, and attorneys	20
Mental incapacity and care	24
Access to records and making complaints	26
How do I comment on care or see my records?	26
Making a complaint about services or charges	27
When should I go to my Councillor or MP?	26
Resources	
National support organisations	29

Foreword

by The Rt Hon The Lord Morris of Manchester AO QSO

Dear Reader,

Family carers and the disabled relatives they care for, need all of the help they can find. More especially, they need the best possible information on who can help them and how.

So, I am delighted that **Caring Matters** has put together this extremely valuable new guide for them, tackling as it does so effectively, such questions as: What help is available? Where do I get it? and How can I change things I don't like?

It gives information on new support the Government is providing; on what local, health, and social services authorities – among other agencies – can do to make life better for disabled people and carers alike; as well as on what to do and when to do it, so as to secure the right help, from the right source, at the right time.

You will also find here a listing of the organisations, with contact details, best fitted to provide information relevant to specific needs. The guide reflects great credit on **Caring Matters** and I pay tribute to its founder, Ruth Windsor, in particular.

Reading the guide in draft reminded me of the comment of a hard-pressed friend of mine in Lancashire whose daughter was disabled from birth. "A thimbleful of practical help," she said, "is worth more than buckets of sympathy."

That's what this guide is all about – practical help for people in pressing need – and I warmly commend it to you.

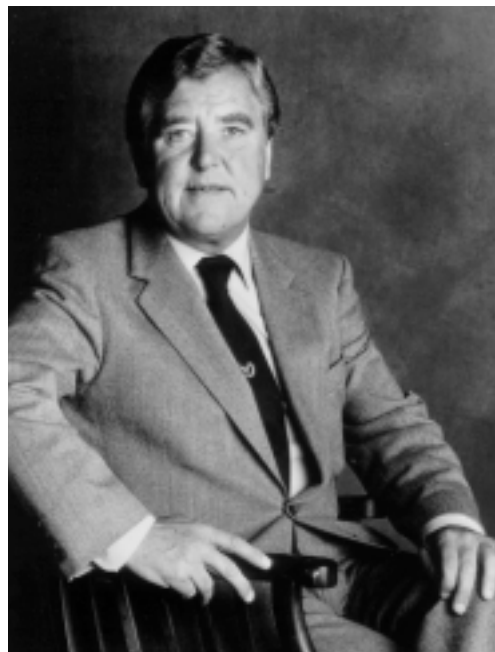


Photo courtesy of Derek Kinrade, National Information Forum

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Do you or a relative need help after leaving the hospital?

Whilst in hospital, you should speak to your named nurse if you need help with: dressing, bathing, toileting, getting around, cleaning, shopping, other tasks around your home, taking medicines, pressure sore care, or managing urinary or bowel continence.

Your nurse can arrange prescriptions and follow-up appointments. He or she can also ask the hospital social worker, discharge co-ordinator, or local authority care manager to assess your needs. If you do not want to move into a care home, be sure to tell them.

Professionals assessing your needs decide what services they can provide. They may decide to arrange help at home, or to change the place where you live. Social services and your health care providers have a responsibility to tell you what services that they can arrange to help you remain at home or move into a care home.

It is a good idea to ask them to describe what procedures, priorities, and rules they use to decide whether they will provide services, and if they will help to pay for them.

Ask them to explain about how their rules apply to your situation. Make an effort to understand how they made their decisions. Keep a file of forms, letters, and minutes of meetings that you attend.

Primary Care Trusts

A person from your primary care trust should send you a letter telling you the needs they will meet:

- when you require frequent treatments or appointments at the hospital, with the doctor, or nursing care
- when they will pay for rehabilitation and for how long
- whether you should be discharged into a residential or nursing home, or

- when local and/or health service providers need to provide help at home.

You have a right to ask for a review, when you disagree with their decisions. You can make a complaint if you are unhappy about how they applied their rules to your case. (See page 27.)

Social services

Social services may charge the person receiving care and their husband or wife for services. Social services may review the income and property of the person who receives the care. They should tell you what you would need to pay for the services before you agree to the care plan. (See page 11.)

Who should decide what help I need?

You may need help with tasks at home, or with getting up, or walking. If you cannot afford to arrange the help, ask your social services department to assess your needs.

Your social services department is listed in the Yellow Pages as a department of your local authority. Care managers assess your needs and whether you qualify for their services.

If you are in the hospital, or need help dressing or getting around, several care professionals may meet with you to see how they can help.

This meeting may be called a **multi-disciplinary assessment** or **case conference**. Your doctors, nurses, therapists, home help, care manager, and representatives of the primary care trust may attend.

Everyone discusses your care needs and possible arrangements. This team works with you, and possibly a family member or friend, to arrange your care plan.

When you meet with the care manager, or attend an assessment meeting, it is a good idea to invite a

person that you trust to attend. This person can give you confidence, help you to remember what was said. They can make sure that none of your needs are missed in the discussion. If you make some notes of what is said, it will help you to remember later what has been agreed.

The people assessing your needs are very practical. They will look at what help you need with dressing, bathing, toileting, preparing meals, cleaning, shopping, getting around, and claiming benefits. They can check that your home is safe. They may loan equipment to make tasks easier.

Your assessment will determine the support they can offer you. The professionals may recommend that the best way to meet your needs is a hospital stay.

Or, they may arrange help at home, or offer you a place in sheltered housing, or a residential or nursing home. The assessment may result in a decision that you do not need the services they provide.

Not all care is free. If social services arrange your care, they will look at the value of your income, savings, and assets. The result of this "financial assessment" may mean that they may charge you for the services.

Be sure that you understand what you are agreeing to before signing care plans or financial assessment forms.

Note that once you have signed the financial assessment form, you may be liable for costs. Your liability may not be apparent until months or years after the care costs have been incurred.

Make sure that you know whom to contact with questions that you may have after the meeting.

Ask for information about how they decided on your care plan and how to make a complaint, if you are unhappy with the result of the needs assessment.

It is a good idea to keep a copy of all letters, care plans, and minutes from meetings. Send a note to the people involved when you are unsure of something noted or you disagree with what has been recorded in the minutes.

What can I expect from my needs assessment?

You can expect clear advice and information about: how they have decided what you need; what services can be provided; and what you would have to pay for your services.

Ask them to explain any terms, comments, or agreements that you do not fully understand. Do not assume that they will explain everything that you need to know.

A good example of this is when you hear someone say they will fund the costs of services. Social services may fund care arrangements; but then charge you for what they have paid.

You can expect your information to be treated confidentially, and to:

- have your own and your family's wishes and choices listened to and considered fully
- be told about decisions affecting you and the people who provide your care
- be given written details of the care arranged for you, and of any payment they expect you to make.

Going home from the hospital

After you agree your care plan with the care manager, you should receive a copy. The care plan will describe what each person or organisation will do. The service provider should tell you what you would need to pay.

You may not agree with the services they offer, or what they want to charge. You have the right to ask for a review of their decisions.

When you return home, the care manager should visit. They should make sure that your assessed needs are being met. If your needs are not being met, agree the changes they suggest

Help at Home

Who can help with dressing, shopping, cleaning, or preparing meals?

Home care workers are also known as care assistants, personal assistants, or domiciliary care workers. They have an important role in helping with care at home.

Domiciliary care workers provide what is known as personal care. Personal care includes tasks that involve touching your body. Bathing, dressing and undressing, and going to the toilet are examples.

Home bathing may be provided in a separate package.

Care assistants carry out tasks like: shopping, cleaning, preparing meals, and collecting pensions.

Personal assistants carry out all of the tasks listed above, as well as escort you wherever you want to go. Personal assistants are often employed with money from direct grants.

You may choose to hire people to help with care at home. Local service providers can give advice and support.

Social services may ask you to pay toward your care costs that they either provide or arrange.

If you are married, your spouse may be asked pay toward care costs. Social services charge according to your wealth and local policies.

Primary care trusts provide home nursing services to help you with tasks like managing urinary or bowel continence or injections. These services will be provided free of charge.

Please note that care staff and volunteers may not be allowed to accept gifts.

Write a note of appreciation or give them a box of biscuits or chocolates when you are feeling the need to show your appreciation.

A complimentary letter to their employer or manager is also appreciated.

Home care services

There may be other help available. Ask social services about other services that are available locally.

Examples of other services are:

- **Day care:** Local authorities and voluntary agencies may provide care in centres and transport. Day care is a chance to get out and spend time with others. It may allow carers the opportunity of being able to work, or to have time for themselves.
- **Meals:** Food can be provided as meals on wheels (often frozen and needing re-heating), or at lunch-clubs and day-care centres.
- **Continence services:** Some councils arrange the collection, washing, and delivery of laundry items for people coping with urinary or bowel continence problems.

GPs and district nurses often provide urinary or bowel incontinence supplies. They may provide pads, wipes, gloves, urinary catheters, urinals, or special plastic sheets free of charge.

Tell your GP about the continence problems. The proper care routine can help to maintain the person's dignity and make caring easier. They may help to find a continence management service that can give advice, training, and other services.

Your GP may:

- prescribe medications
- refer you to an incontinence specialist, or
- have a community nurse provide support.

Equipment available for helping at home

You may receive equipment to help you move about your house more confidently, safely, and quickly as a result of your needs assessment. This equipment will be on loan to you from the local authority. It should be returned when it is no longer needed. There may be a charge for using equipment.

Occupational therapists (OTs), from your local council or health care provider, can assess your needs for equipment or adaptations home.

They may arrange to have the height of chairs or beds altered to make getting about easier. They may make suggestions about the modern aids that can increase your safety and independence.

Special equipment that may be available includes:

- dinner plates with high edges to keep the food from spilling
- plates with a special finish to keep them from sliding around
- cutlery with curved handles
- kettles with safety features to prevent scalding
- special pens and pencils
- handles to help people with arthritis carry plastic bags
- rails
- raised toilet seats
- special commodes or shower/bathing equipment; and
- telephones or television for people who have trouble with seeing or hearing.

What is an alarm scheme?

Alarm schemes provide a service to older and disabled people. Alarms help people, who may need emergency assistance, when they are at home alone.

An alarm enables the person who needs assistance to contact the control centre.

Pressing a button on a pendant that you wear around your neck will contact the control centre. Or, you may contact the control centre by pressing a button on an alarm box or keypad.

Some alarms that are worn near your waist or wrist, alert the centre if you have fallen.

The alarm reaches the operators using a telephone line. The alarm operator may speak through a speaker to ask what you need. You may be able to tell them what you need through a speaker.

The operator can alert friends or neighbours who hold keys to your home. They may contact emergency services, when it is needed.

The organisation that provided the alarm may charge you for the alarm service. Please return the alarm when you no longer need to use it.

Do you need a home improvement grant to stay at home?

If you need major changes to your home, ask your local authority for help. Your local authority provides Home Improvement Grants. **Disabilities Facilities Grants** may also provide improvements including: widening doors; building ramps for wheel chairs; and moving a bathroom downstairs.

Selecting home help checklist

Often the care workers or assistants will be employed by independent agencies, rather than by your council directly.

If you are involved in selecting a home care worker or domiciliary care agency, it is important to give the decision a lot of thought. When choosing a domiciliary care agency, consider the following.

- Is the agency approved, used, or recommended by your local social services department or primary care group? Can they provide references to support this?

- Does the agency have experience of working with clients who have similar needs to the person needing care at home?
- Can they provide references of clients with needs similar to those of the person they would be caring for?

Examples include:

learning, mental, or physical disabilities • cognitive impairment such as dementia, forgetfulness, confusion, mental illness, or the inability to count money or make sound decisions • urinary or bowel incontinence • language, communication, or cultural needs • and people with injuries or specific illnesses.

- Does the agency train its staff before they start work, and provide continuous training?
If you are not working with an agency, can you assess the person's ability to carry out care tasks?
- Does the agency vet its staff for working with children and vulnerable adults?
If you are not working with an agency, how will you vet the person's personality and background?
- Does the agency provide insurance cover for its staff?
If not working through an agency, what insurance cover should you or the care worker have?

Consider these issues when selecting home help:

- Has anyone investigated the care worker's work and personal history?
This is important when the person needing care is very dependent upon others. The care worker(s) will have unsupervised access to your loved ones.
- What arrangements are in place if the care worker is unable to come to work at the last moment?
- Do the workers fit in with the patterns of the person needing care and the family members? If not, can you reach a suitable agreement before caring takes place?
- Do the carers and person needing care get along together? Is the person receiving care happy during and after the time they spend with the carer?

- Can the carer meet the care and communication needs of the person they care for? If not, how and when will the care worker learn the skills?
- Do you have a system in place to communicate with the care worker during or after each care session?

A care diary for the care worker(s) to keep notes and receipts is a good way to record personal and entertainment activities, spending, and health.

The diary is not an adequate replacement for speaking with the care worker about how things are going.

- Is there a good balance between the people providing care? Would a change in the schedule or the number of people providing care work better?
- Do the care workers work with and in support of family members? Do they rely too much upon family members when they are available?
- Do the care arrangements reduce the strain on you, or increase it?
- The checklist is only a guide for things to consider when seeking help at home. Every care situation has unique requirements related to the care needs of the person and the place the care is taking place.

We are grateful to Brian McGinnis OBE and Mencap for their contributions to this section.

What are direct payments?

People who have disabilities may receive money from social services for hiring personal assistants. Carers may receive money for services that help them to continue caring.

This money may pay for part of care needs to help people remain at home. Social services may provide services to complement help that is paid for by these direct payments.

Social services departments in England and Wales must offer to pay these payments to people who meet certain criteria.

The person needing care can neither hire people who are living with them, nor relatives, as live-in personal assistants.

Extreme circumstances may permit an exception to this rule.

To receive direct payments, you must ask for an assessment and state that you want direct payments.

You must meet the following restrictions.

- You must have a disability and be at least 18 years of age. You may be able to receive a payment under the Carers and Disabled Children Act 2000 if you are 16 or 17; and
- your assessment results must agree that you have care needs; and
- you agree that you want direct payments; and
- you can manage the direct payments on your own or with the help of others; and
- there are no criminal or mental health reasons for not paying you direct payments.

Ask your local social services department for an assessment, so that they can decide how much care they will fund.

This total number of hours determines how much money they will pay you in a direct payment.

Make sure that you understand:

- the definition of disability against which they have decided your ability
- local priorities of deciding whose needs are most important, and
- the rules or eligibility criteria they have used to decide how many hours of care that you need.

If you do not agree with their decision about the number of hours they will fund, or whether you are eligible to receive direct payments, write to the

director of social services asking for an appeal of their decision.

The Independent Living Fund may provide additional money to pay for your home care services or support.

The National Centre for Independent Living provides details of social services departments and local support services for people with disabilities. They also provide employers' packs for hiring personal assistants.

Support for Carers

Are you looking after someone who cannot look after him or her self?

Are you are helping someone with tasks like dressing, washing, shopping, or cleaning?

If the answer to these questions is "yes", you are referred to as a "carer". If you are under the age of 19, you are called a young carer.

You may be entitled to a benefit called the invalid care allowance (ICA). This benefit recognises your contributions and the time you invest in caring.

The number of hours you care, your income, and the amount of help the person needs determine whether you can claim this benefit.

The person you are looking after must be receiving either the Attendance Allowance, or the middle or higher rate of the care component of Disability Living Allowance.

Please contact your local social security office or carers' group for more information.

When you are caring for someone, it is important to do your best not to take away their freedom of choice, or restrict contact with people they would like to speak with or see.

Your support of their independence and dignity will benefit you both.

What is a young carer?

Young carers are aged between five and eighteen years old. They help to look after a relative or friend who is ill, has a disability, is affected by HIV or Aids, has a mental health problem, may take drugs, or drink too much alcohol. Sometimes young carers spend time listening when the person they look after is sad or depressed. They may also worry about the person they look after.

Young carers may help with cleaning the house, cooking, washing, housework, shopping, and managing money.

Some young carers help the person they care for with tasks like going to the toilet, having a bath, and dressing. They may also need to help the person get out of a chair or bed.

Young carers may worry that the family will be broken up if someone learns that a parent needs care. The only time this could be a worry is when there is the possibility of danger to the children or family members.

How can I recognise and help a young carer?

Young carers are hard to find and may choose to remain anonymous.

Caring affects each young person differently. Some ways that caring for someone affects young people include:

- often appearing to be tired or depressed
 - asking to use the telephone often
 - missing school
 - finding it hard to concentrate in class because of worrying about the person they care for
 - not completing schoolwork on time
 - arriving late to school because of caring tasks or taking brothers and sisters to school
 - not doing as well as they could in school and other activities
 - not joining activities that happen after school or weekends
 - having no one attend parents' evenings or other parent activities
- Young carers may be afraid of what may happen to them and their families if someone found out they were caring for someone.
- You can help young carers by:
- looking for the signs of a young carer
 - offering to listen to their worries and to find help
 - telling them what is possible and asking them what help they want
 - sharing information about local help and young carers' groups
 - contacting social services for a carers' assessment if the young carer would like one
 - finding a way to meet with parents if they are unable to come to parent evenings
 - being flexible about when, where, and how homework is done
 - allowing the young carer to use the phone in privacy when needed
 - finding a way to help the young person join in after school and weekend activities
 - getting help from the education welfare officer or other educational support when needed
 - discussing caring and disability in the classes
- having a sore back because of helping a person to move around
 - having ulcers, nervous tics, or other stress-related conditions
 - having low self-esteem
 - being bullied

- creating community caring projects for the school or class, and
- seeking advice if child protection is an issue.
- Difficulty with walking, balance, writing, swallowing, chewing, speech, hearing, seeing, bathing, toileting, dressing, or special food requirements?

Young carers may not realise that there is help in the community and who can provide help, and will not let others know.

We are grateful to the Kettering Carers Centre for contributing this information. Kettering Carers Centre, 1 Meadow Road, KETTERING, Northants NN16 8TL. Phone: 01536 414 259

How do I write the care plan?

It is a good idea to write notes about the care the person receives. Consider including the following points as they apply to you.

Contacts, appointments, & medications

- List contact details of GP, consultant(s), district nurse, physiotherapist, speech therapist, occupational therapist, care manager, day care centre, and family or friends to contact in case of an emergency.
- Describe care services provided or supported by local and health care providers or your GP's surgery.
- List medical treatments and regular appointments. Medications, dosage, frequency, and how they are given (for example, in liquid, with food, before or after meals?)
- List any payments you must make for the cost of services and when.

Describing care needs

- Does the person require care because of illness, injury, or age?
- Will the symptoms remain the same or get worse in time?
- List the physical or mental symptoms (forgetfulness, mood swings, coughing, spasms, bleeding, tremors, or seizures?)
- Describe regular care procedures including disinfecting, sterilising, laundry and washing for urinary or bowel incontinence.

Personal preferences

List likes, dislikes, hobbies, favourite foods, activities, and the time of day the person likes to get out of bed, have meals, take naps or enjoy radio or television programmes.

Helpful notes

- Update the care plan as needs, contacts, or medications change.
- Provide a copy of the care plan to a neighbour, the GP, district nurse, home help, and employers of home help in an emergency.
- Keep a document folder with copies of all forms and letters relating to care, social services, benefits, and the care diary.
- Record phone calls relating to care matters, noting the date, time, phone number, person you spoke with, and a note of what was discussed in a notebook (care diary).
- If decisions or requests for benefits, support or service were made in a phone conversation, write these in this diary. Send a note stating what was agreed or requested.

This diary will be helpful to others. It may be your best friend. Note changes in care staff, contact details, during respite, or who to contact in an emergency.

Reassurance

- In case of an emergency, it may be helpful to keep an index card, stating that you are caring for someone in your car, wallet, bag, or jacket. Mention the name of the person(s) you are caring for.
- Include details of how to contact the GP, care manager, home care agency, or someone who is close to the person.
- You may want to avoid including your or the person's contact details on the card, in case of loss.

Taking care whilst caring

Be sure to ask about:

- ways to move a person and lift them without hurting yourself
- helping people to climb and go down stairs, and
- learning to push a wheelchair over kerbs and stairs.

When making a GP appointment, tell them that you are caring for the person at home. Ask for priority and extra time when making your appointments. They may give you a “double appointment” for you or for the person receiving care.

Ask the GP or consultant questions about possible side effects of medicine and related care issues.

High blood pressure, diabetes, kidney, and breathing problems may have some procedures or tests that you could do at home to keep stop the condition from getting worse.

Caring for yourself

Stress, fatigue, and never-ending care responsibilities can take their toll on people who care for others.

Maintain your own health by:

- getting daily exercise. A brisk walk or exercise with a video or television programme help to get rid of stress whilst keeping your body flexible and fit.
- spending time out-of-doors
- having a healthy diet, and
- relaxing. Find time to read, solve crossword puzzles, or enjoy another pastime each day. Meditation and relaxation tapes are helpful evening activities.
- Aromatherapy, massage, reflexology, and facials may also be beneficial.

Can others help with caring?

Ask for help if you are in a caring environment where you cannot leave the person for whom you are caring alone. For example, ask a friend or neighbour to give

you a break by providing short periods of care a few times a week.

Local carer groups may provide an afternoon of care once or twice a month. This can allow you to be on your own at home or to have some time out with friends. Ask for help if you are awakened throughout the night.

Ask social services contact to provide an assessment of your needs when caring needs change. They may also arrange home help, respite, or day care services.

Day care provides stimulation and a change of scenery to the person receiving care and a break for you.

Support from social services varies throughout the country. Some voluntary organisations provide respite services. Charities may support well-known conditions or diagnoses.

Your care manager, GP, consultant, or local yellow pages are good starting points for information and support.

Taking a break from caring

Respite care is an alternative care arrangement that gives a break to the person who looks after someone at home.

Respite can take place for weeks, on weekends, or at night-times. Care arrangements vary according to individual needs and local policy. Social services, the health care service provider, or family and friends can arrange respite.

They can arrange for either the person providing or receiving care to leave. The person receiving care may find it stimulating to go to another place. The person providing care may enjoy staying in another place.

The social services department or health authority may pay for all or some of the costs of respite care.

In other circumstances, you, your husband, or wife may need to pay some or all of the costs.

Ensure that you know what expenses are covered in the agreement with the home providing respite care to avoid unexpected charges or costs.

This break is a benefit to all people involved in the care environment. Consider the needs and wishes of everyone when making arrangements.

The importance of seeing friends

If you are caring for someone, it may be difficult to leave home if they are ill, depressed, have mental health problems, or find it difficult to move around. As a result, contact with friends and family may decrease and isolation and loneliness can step in.

Use your creativity to develop interesting activities. This will keep friends in touch and make time pass more quickly and enjoyably.

The activities need not be extra work for you. Invite people to bring specific ingredients and give everyone a task in preparing a meal.

Cultural or music evenings can result in lively visits and happy memories. Videos, sports, and special TV or radio programmes can be entertaining.

Involving others in care creates a stronger care team. It can also help you, and provide more stimulation and support for the person receiving care. If family and friends are supportive, be honest with them.

People may want to be helpful, but are unaware of what to do. Tell people how they can be helpful. Ask them to write, phone or visit at certain times, help with chores or household tasks, bring meals or run errands, or give you a break from caring.

They could also pamper you with vouchers for trips to the local gym or hair, beauty, reflexology, or massage appointments.

Expressing your thoughts and feelings

You may wish you had someone to confide in about your feelings and abilities to cope with caring. Voluntary organisations provide helpful listening and advice services. People in similar caring situations may also be supportive listeners.

When you have no one to speak with, a pen and paper may suffice. Write a letter in a quiet moment, or when you are worrying or upset about something. This letter can be to a long lost friend or someone else close to you. Let your thoughts and feelings flow from pen to paper.

Write about what you are thinking or feeling, what is upsetting you, what you can do to resolve it, the good and bad aspects of the situation or decision, and what aspects of the decision you consider most important.

This is a convenient and non-threatening way to express yourself. You may see a resolution, or even feel better before you have finished writing the letter. You may decide to send the letter, or keep it in a safe place to review later. You may choose to destroy the note to ensure confidentiality.

Letter writing is helpful in times of sleeplessness, loneliness, isolation, panic attacks, or making decisions. Keeping a care diary provides daily reflection and may be helpful later.

Caring from a distance

A person you care about needs care that you can no longer provide. A loved one receiving care may live far away. You may still be providing care and support from a distance. You may find some aspects of care more challenging.

- Your concerns or needs may seem to be pushed aside.
- You may be concerned about signs of the person's care needs increasing.

- You may be concerned when the person cannot manage his or her own money.
- You may be labelled as an ex-carer.
- You may be unprepared or unable to sort out services and funding with health or social care service providers.

Discuss your concerns with the manager or matron of the care home. If your concerns remain unresolved, contact the authority that inspects the care home.

Loneliness, worry, and feelings of guilt are common when you are unable to provide care for a loved one. Your GP or carers' group may provide listening or counselling services.

You may have more discretionary time than when you were caring for someone at home. Volunteering your time and services may help you to feel better and benefit others.

Charging matters

Who pays for help at home?

Local authorities and primary care trusts have rules about what you should pay. Each authority applies their local charging policy to their eligibility criteria, to decide what services to arrange and when you need to pay.

Some services will be free; some will be charged for at a flat-rate fee; and some may be charged for at a rate that is dependent upon your 'means'. The charging team will look at your benefits, savings, and other income.

The care manager will then tell you about the services that you can have, and how much you will need to pay. If you receive services because of your personal wishes, rather than what they decided that you need, you may need to pay all of the costs of the services.

In some situations, you may pay the local authority directly. Or, you may pay the service provider directly. They may ask your husband or wife to pay towards your care.

The care manager or charging team should tell you what you must pay before you accept their services. The people arranging your care should tell you how they have decided what you must pay.

If you do not agree with them, you may ask them to re-consider their decision. Ask a local carer or advice organisation about whether you need to pay toward your care or services.

Please note: Some financial forms ask for information about the husband's, wife's, children's, or parents' money. Only the person who is receiving care or services, needs to share information about their personal income and assets.

Ask your named nurse or care manager to explain discharge procedures, eligibility criteria, social services priorities, and charging policies as they relate to your situation. If you are unhappy with the amount you are required to pay, you may request a review.

What is a charging policy?

A charging policy is the rule that your social services department uses to decide when people need to pay for their own care. A combination of you, your husband or wife, your social services department, and your health care provider may pay toward care.

When social services and the health care provider both pay for your care, this is called "joint-funding." When the social services pay towards care costs, they may charge you for all or part of the money they have paid.

The social services department may assess your money and property. After they review your finances, they should explain their reasons for charging you.

What are eligibility criteria?

Eligibility criteria are the rules used by your social services or health care provider when they consider providing or funding services.

By using rules, called criteria, agencies can ensure that their limited resources can help those people most in need, or 'at risk'.

Every health and social care provider is required to publish documents describing the criteria they apply.

Deciding who is eligible for services depends upon several factors. For example, you may be totally dependent upon other people to look after you. Your home may not be a suitable environment for care.

Or, you may not have friends or relatives to help you. In these circumstances, you would be identified as being at risk.

Minimising your risk is a priority and you should be eligible for services.

What is continuing NHS care?

The NHS may provide your care free of charge when you are very ill or disabled and need expensive treatment.

A patient must need the care of a specialist physician and 24-hour-a-day nursing services. The NHS provides the following continuing care services:

- respite care that provides a break from caring
- rehabilitation to help a person re-gain their independence
- recovery from an illness or operation
- palliative health care to help someone will not live much longer
- continuing in-patient care, and
- specialist support for people living in the community or in nursing or residential homes.

Local service providers agree how they will meet local needs. They create their rules according to their local resources and Department of Health guidance.

Am I entitled to free continuing NHS care?

You may have complex care needs and require regular medical and/or nursing care. Your primary care trust may have the duty to continue to care for you.

Each health care provider has its own rules for when they will provide free continuing NHS care. Ask for information about eligibility criteria for services and funding.

Ask your named nurse or care manager for their leaflets. They should explain how your situation relates to the criteria for services, and help with paying for care. Your service provider should explain when you could receive free care.

Your care managers should make sure that you have understood how the criteria, priorities, and charging policies have been applied to your situation. You will need to agree the care arrangements and the amount you will pay towards care.

If you do not agree with their decision, you have the right to ask for a review of the decision, before agreeing about your care.

You may be dissatisfied with the result of the assessment of your eligibility for continuing NHS care. You may request a review to have the decision re-evaluated. (See the Making a comment about services section.)

Care homes

What should I consider when moving into a care home?

There are three major kinds of care home: sheltered housing, residential care, and nursing homes.

Sheltered housing provides accommodation for people who are active, independent and able to cook for themselves. A warden stays close by to keep a caring eye on them. The warden helps people in an emergency. In some cases, the wardens are on site. In other settings, residents are linked to the warden's home or emergency services by an alarm.

Residential homes provide a place to live with either a single or shared bedroom, communal dining and leisure areas, meals, and laundry. They encourage you to maintain your independence, and normal routine.

Shared rooms provide stimulation to those people who are sharing. Sharing may prevent people who are confused or forgetful from becoming too isolated.

Nursing homes provide all the facilities and services of a residential home. The difference is they provide twenty-four hour nursing care.

When you move to a residential care or nursing home, the care managers should review your placement with you and the care home staff every year.

It is a good idea to let the people who arranged your placement know when you have any problems with the care home.

Care home management and staff may not be allowed to accept gifts or money from residents.

When you want to show your appreciation for their care, write a complimentary letter to the employers or care staff. Small gifts like biscuits and chocolate are appreciated.

Choosing a care home

The person that manages your case will discuss the choices of care homes with you.

In considering a care home, check that the care provider will:

- fulfill your needs
- treat you with dignity and respect
- protect your money and property
- provide a receipt for valuables stored in the home's locked storage
- protect rights and meet the needs of a person who may be confused, forgetful, or needs others to manage their money
- ensure that you maintain your personal freedom and individuality
- offer the quality of life that meets your physical, emotional and spiritual needs
- allow you to make your own decisions, when you are capable of doing so
- have a pleasant and welcoming appearance, fragrance, and atmosphere,
- enforce a no-gift policy that care staff and managers must follow, and
- have procedures in place describing when and what information they share with doctors and family members.

Social services may also help you to visit homes and to have a trial stay in the home of your preferred choice. A trial stay is vital if you need much attention or you have special needs.

Look at the inspection reports on the home. These will be available at local libraries and at the home.

Discuss with the home manager what furniture, belongings, or pets you could take into the home. You will also need to discuss what will happen to your own home.

Can I choose my care home?

If you have the funds to pay for your care, you may choose any home that will accept you. When social services or your health care provider are involved in arranging your care, you may choose a home run by the local authority, a company, or a charity.

The home does not have to be in the same county as your local authority. If you wish to move to be near friends or relatives, you can do so.

When social services or the health care provider arrange your placement, the home you choose must be suitable for your assessed needs. It must comply with any terms and conditions set by those authorities. In addition, it must not cost any more than the local authority would usually paid for someone with your assessed needs.

Make sure you can afford your chosen care home over the long term. Care fees increase each year. Increasing care needs may also cause home fees to increase. When costs are more than the local and health authority will contribute. Costs may be more than the local and health authority will contribute.

You may need to move to another care home, if you or your family cannot afford to pay the additional costs of care.

However, you may be entitled to funding from the NHS if you meet the continuing NHS care criteria.

Approach your service providers for leaflets and explanations about whether you qualify for NHS funding.

Who pays for my stay in a care home?

Your stay in the home may be considered temporary for up to fifty-two weeks. The local authority will allow you to keep income that is needed to cover your home commitments during this time.

If your stay is to be permanent, and you have money and property totalling more than £18,500, then you are expected to pay the full cost of residential or nursing home care.

If you have assets worth less than £18,500, they will use a 'means-test' to decide how much you have to pay.

The local authority will put all of your income and benefits towards the cost of your stay in the home. It will make up the balance to the maximum it is prepared to pay for that type of accommodation.

From your income you will be able to keep currently £16.05 a week as a personal expenses allowance. If you have between £11,500 and £18,500 you have to pay an additional amount, called capital tariff, of £1 for each £250 between these two figures.

A nurse from the primary care trust will assess new resident's nursing needs. This assessment will determine what part of the care home fees will be paid by the NHS for nursing care. The NHS will pay for nursing care that is provided, delegated, or supervised by a registered nurse in residential care homes.

However, you may be entitled to full funding from the NHS if you meet the continuing NHS care criteria agreed by the local authorities.

Make sure you can afford the care home that you choose over the long term. Care fees increase annually. Increasing care needs will cause home fees to increase.

You may need to move to another care home if you cannot afford to pay the increased fees.

You have choose to go to a home that costs more than a local authority will pay. Your family or friends may be allowed to pay the extra, if they are willing and able. When others pay the extra amount, this is called a "top-up".

Keeping your old home

Your current home is not counted in the financial assessment if your partner (married or unmarried), or a relative who is over sixty or is incapacitated continues to live in it.

There is also discretion to ignore the property, if a carer who gave up his or her own home to care for you lives in it.

Giving your home away

It is not a good idea to give your home away to avoid selling it to pay for care. The local authority can refuse to fund your care costs if they discover that you have done this. Think about seeking the advice of a solicitor that specialises in issues affecting the elderly when considering giving expensive gifts.

My partner needs care How does this affect me?

Social services only have the right to 'means-test' the person who requires the care. They will take into account any capital the person owns and all their income. The local authority can ask a spouse to pay towards care costs, if they feel they can afford it. This is called a liable relatives' contribution, for which there are no fixed rules for calculating.

We are grateful to the Nursing Home Fees Agency for contributing the information in this section. (See resources at the end of this guide.)

Legal matters

When is someone considered mentally incapable?

Decision-making is something we usually take for granted. An injury, illness, or other condition may cause a person to be unable to make decisions. Or, a person may not be able to tell others what they think or want. Matters can become complicated.

The capacity of older people may be reduced by dementia. Mental illness can affect mental capacity in varying degrees and for varying periods.

A learning disability may permanently limit a person's capacity. Or, people may suffer a reduction in mental capacity through a brain injury or stroke.

If a person's capacity to take decisions is affected in some way, an act or transaction they make could be invalid.

That person may need special help to make decisions or manage finances and assets.

A person with such problems will not automatically lose capacity to make all decisions. But there are circumstances where their decision will not be legally binding.

In order to establish a person's incapacity, medical evidence may be required and legal advice is likely to be essential.

Generally speaking, capacity depends upon the ability to:

- understand the act or transaction
- understand the consequences of taking or not taking the action
- understand the consequences of making or not making the transaction, and
- understand and weigh up choices and actually to make a decision or commitment.

It is not always a good idea to try and sort things out informally. You are likely to need legal advice if you are making arrangements to look after the affairs of someone with impaired capacity, or to make decisions for them.

If necessary, an act or transaction which has been undertaken by a person lacking capacity can be declared invalid by a court.

Someone with impaired capacity may need help with managing money and assets or in making decisions.

Another person can be appointed to help the incapacitated person. Different types of appointment include appointees, guardians, and attorneys. Seek advice on all the options, and the best course of action.

Notify the authorities if you are concerned about an attorney, guardian, or receiver abusing their powers or restricting contact with family and friends.

For more information, phone the Enduring Power of Attorney Helpline at the Public Guardianship Office, 0207 664 7327.

Abuse or exploitation

Staff and family members should protect vulnerable people from abuse and exploitation. The Law Society and The British Medical Association produce guidance about this.

People who are vulnerable include:

- people with learning disabilities
- frail and people who have lived long lives
- people who cannot manage their own money and property
- people with mental illness, and
- people who are unable to make decisions about their care and treatment.

Relatives and carers should watch for signs of abuse or exploitation. Where abuse is likely, explain to the person who may have been abused why it is important to tell other people.

Obtain consent from the person to report the suspicions and inform the police immediately. Inform the National Care Standards regional office when the alleged abuse is happening in a residential or nursing home.

A person may be unable or unwilling to consent to a police enquiry. It may be necessary to report the matter to the police without consent. An example of this may be the possibility of other residents being at risk.

This information has been written by the Health Division, RadcliffesLeBrasseur Solicitors, 5 Great College Street, Westminster, London SW1P 3SJ. Phone: 020 7222 7040.

How can you tell if a vulnerable person is being abused or exploited?

Staff and family members should recognise the signs of potential abuse and exploitation.

Anyone who has contact with a person can exploit or abuse them. Abuse can occur in any setting.

Please take notice when observing anyone not treating the person with dignity and respect. Things to look out for include:

- bruises and burns
- physical restraint by a person or equipment
- restricting contact with family and friends
- appearing to be receiving too much, too little, or the wrong medication
- changes in behaviour like flinching, or avoiding eye or other contact with the possible abuser
- shouting, swearing, frightening, blaming, ignoring, or humiliating someone
- using a person's property, money, pension book or other valuables improperly. Are there accounts, receipts, and ways to prove where the money has gone?
- controlling a person's participation in any sexual activity
- not giving a person the correct amount or type of food, heat, clothing, comfort or essential medication, and
- not meeting the person's personal care and toileting needs

Please note that these signs are not exclusive to abuse. The signs may result from moving to another care setting, being unhappy about their circumstance, or be related to the person's condition.

Managing another person's affairs

When people cannot manage their own money as a result of injury, illness, mental incapacity, or disability, other people must take the responsibility of receiving benefits and other income.

People must ensure that money is spent in the best interest of the person owning the money, and protect the person's other property.

A number of options exist for managing the affairs on behalf of another. The right approach depends upon:

1. the amount of money or other assets to manage, and
2. the vulnerable person's ability to communicate, and
3. the vulnerable person's understand the implications of his or her actions and agreements.

Signs of mental incapacity such as confusion, forgetfulness, and loss of concentration may invalidate being able to act on another person's behalf with joint bank accounts, bank mandates, Agency in regard to collection of benefits, or other forms of Agency.

Considerations

Appointees, attorneys, and receivers are obliged to use the money which they manage for the vulnerable person's benefit.

Money may pay for necessities, such as food, clothes, heating, as well as personal and health care. If the person is in a care home, the care package will normally pay for necessities.

If the person lives in a care home or has home carers, make sure that accounting procedures are in place.

Ideally, the procedures will include saving bills and receipts, and noting the person taking the money, the amount they have taken, and change returned. They should record evening and weekend spending and have someone audit the accounts.

Managing others' affairs is limited to their financial affairs. No one has the right to control a vulnerable person's decisions about activities, who they see or communicate with, where they live, or what they wear or eat.

People who are managing a vulnerable person's affairs should not use the person's car, disabled parking badge, or other assets for the benefit of anyone other than the vulnerable person. They may be guilty of exploitation and abuse, if they misuse assets.

What is an appointee?

An appointee is someone who has been given the permission to collect and spend benefits and pensions on behalf of someone who is mentally incapable of managing their own affairs.

Appointees are only used when the person has very little money and property. The Court of Protection should be notified when a person has more assets or income than benefits and a state pension.

The person's local social security office will decide whether the person needs an appointee. They will also decide whether the person offering to act on the claimant's (the person they are representing) behalf is the right one to do it.

The appointee will be able to claim benefits and pensions and respond to enquiries on the on the claimant's behalf.

The money must only be spent on behalf of the claimant. Appointees should keep records and receipts of all money spent.

An appointee can not make decisions about anything besides financial matters. They should not control the person's behaviour or choice in any way.

If you suspect that an appointee is misusing the claimant's money, please notify the local social security office.

What is a receiver?

A receiver is a person that has been appointed by the Court of Protection to manage a person's money and property when the person is incapable of managing their own affairs or communicating their wishes.

Apply to the Court of Protection for a receivership. A receiver may be a friend or paid professional and must produce annual accounts for the Court of Protection.

The Court selects the receiver by considering: the “patient’s” wishes; whether any family members are suitable receivers; how complicated the patient’s affairs are; and the patient’s best interests.

The receiver must get the Court’s approval for spending large amounts of money or unusual expenses.

A receiver handles collecting pensions and income, paying bills, and looking after the “patient’s” property.

Receivers are paid for their expenses and a professional may charge for their services. The Court of Protection and Public Guardianship Office charge both annual and transaction fees for their services.

A receiver should not make decisions about anything besides financial matters. They should not control the person’s behaviour or choice in any way.

If you suspect that a receiver is misusing the donor’s money or property, restricting contact the donor has with family and friends, or is abusing them in other ways, please notify the Public Guardianship Office Enduring Power of Attorney Team.

What is a power of attorney?

A power of attorney is a legal way for one person (the donor) to give another person (the attorney) the authority (the powers) to act in his name and on his behalf.

As a husband or wife, you may need a power of attorney or other form of agency to act on your spouse’s behalf.

Only in exceptional circumstances will an ordinary power of attorney be lawful when the donor becomes mentally incapable.

An attorney should not make decisions about anything other than financial matters. They should not control the person’s behaviour or choice.

What is an enduring power of attorney?

The enduring power of attorney (EPA) allows the attorney to act on behalf of the donor after they become mentally incapable or cannot express their wishes because of illness or injury.

It is a wise precaution to set up an enduring power of attorney when you are fit and well. Preparing this document gives you and your loved ones peace of mind. The enduring power of attorney allows the attorney to act on your behalf after you become incapable of managing your affairs.

You can specify what matters your attorney(s) can handle by giving them either specific or wide-ranging powers. It must be registered at the Public Guardianship Office when the person has begun to show signs of mental incapacity.

Please note that once a person has shown signs of not being capable of managing their own affairs, the authority of the ordinary power of attorney ceases to be valid.

When no EPA has been prepared, the Court of Protection may appoint a receiver to manage someone’s financial affairs when the person has become incapable.

You may consider telling your loved ones about what you want before registration is required. This may reduce the chance of them contesting the registration.

Registering a contested form may be expensive and lengthy. A court-appointed receiver may be appointed to manage your financial and property affairs. A receiver may be a person other than your preferred friend or spouse. They may charge for their services.

An attorney should not make decisions about anything other than financial matters. They should not control the person’s behaviour or choice.

Is an enduring power of attorney the right choice for you?

Creating an enduring power of attorney (EPA) may be a good idea if:

- the person has property and savings, and needs to plan for possibly becoming incapable of managing their own affairs because of old age or mental incapacity; and
- the person understands what the document can do and the potential risk that can result from giving someone else control over their finances; and
- the older person has two trustworthy people to act as attorneys who can act jointly; and
- the family members and loved ones all agree actions to be taken in the best interests of the older person.

This last point is important. Bickering or other problems can be costly if the registration is contested. and can create more difficulties if people do not agree what measures need to be taken when carrying out responsibilities.

It is worth remembering that the vulnerable person needing protection does not have the Court's protection until the EPA is registered.

People considering applying for an EPA registration should realise that it is an onerous responsibility. An EPA is effective for protecting a person's finances and property.

If a registration is obtained, or appointeeship or receivership are agreed within families, it is hoped that nobody will challenge the day-to-day decisions being made.

Hopefully, decisions will be made in the best interest of a family member who is not competent to make their own.

However, disputes are frequent.

EPAs should not be created for people who:

- do not understand what the document does and the potential abuse that could result from giving someone control over their money, assets, and property, or
- receive only small pensions or benefits and have no other income or property, or
- have learning difficulties and lack the capacity to create an EPA, or
- select attorneys who are unaccustomed to managing affairs associated with the donor's property and finances, or
- have family members and loved ones who don't trust one another, or
- out of kindness, may wish not to expose a loved one to the "risk of temptation" or suspicion, or
- are affected by mainstream psychiatric illness - especially revolving door cases, where you need to register the EPA, de-register, register again, and so on, or
- have won damages awards. It is not recommended to have a EPA for someone who has won significant damages, because of the lack of security and accountability for the settlement.

If, for example, the NHS has to pay £3,000,000 in damages to someone, there is a public interest in ensuring that the damages are managed properly with a view to lasting for the whole of the patient's lifetime.

We would like to express our appreciation for the contributions of Simon Kenton, Brian McGinnis OBE, Ian Purvis, and Andrew Parsons to the content of this page.

What is important when preparing the enduring power of attorney form?

Purchase an enduring power of attorney (EPA) form from a solicitor or legal stationer like Oyez Stryker. Prepare the form with the help of a solicitor if you have any questions about:

- the form, what it says, or how to fill it in
- its registration

- whether the person choosing an attorney understands what the document does, and
- whether the person understands that they are allowing someone else to take control of their own money and property.

There must be no doubt that:

- what you are proposing is lawful
- you understand what powers the form gives your attorney(s) or people who can make decisions on your behalf, and
- you understand what the use or registration of the document allows the attorney or person you give authority to do.

Seek advice if there can be any doubt about your ability to understand what you are signing. Obtain medical proof of your understanding from your GP or advice from your solicitor.

They will ensure that you understand the implications of the powers (authority) you are assigning (giving to others) before completing the form.

Can someone contest the registration of an enduring power of attorney?

Reasons for not registering an enduring power of attorney include:

- that the enduring power is not valid. This is usually because the objector considers that the donor did not have the mental capacity to make a valid power.
- that the power no longer subsists, which means that the donor has revoked the power.
- that the application is premature, i.e. the donor is not becoming mentally incapable of managing his or her own affairs
- that fraud or undue pressure was used to induce the donor to make the power. The objector needs to prove three things: that the donor was induced to make the power; that pressure was used to induce this; and that this pressure was undue.

- that the attorney is unsuitable to be an attorney. This could be for all sorts of reasons. But objectors should remember that attorneys are the donor's choice, even if they are not the attorneys that the objector would have chosen.

These are the only grounds on which objections to the registration can be made.

What is the legal test of capacity to make an enduring power of attorney?

The medical evidence should show whether the donor was capable of understanding, when making the power:

- a) that the attorney will be able to assume complete authority over the donor's financial affairs as specified by the powers assigned;
- b) that the attorney will in general be able to do anything with the donor's property which the donor could have done; and
- c) that the authority will continue if the donor should be or become mentally incapable;
- d) that, if the donor becomes mentally incapable, the power will be irrevocable without confirmation of the Court of Protection.

What is the legal test of capacity to revoke an enduring power of attorney?

The medical evidence should show that the donor was capable of understanding the following points when the power was revoked:

1. who the attorney is or attorneys are
2. what authority has been given to the attorney(s)
3. why it is necessary or expedient to revoke the enduring power of attorney
4. the foreseeable consequences of revoking the power.

For more information, contact the Enduring Power of Attorney Helpline at the Public Guardianship Office, 020 7664 7327.

We are grateful to David Richards of the Public Guardianship Office for his contributions to the enduring power of attorney section.

The Public Guardianship Office

If you need advice or help with managing another person's affairs, contact the Customer Services Advice Unit at the Public Guardianship Office in England and Wales.

Advisers at the office are not allowed to tell you whether an enduring power of attorney: is the right document for your situation, or has been prepared correctly. Phone a solicitor or legal advice centre for information about your situation. The Public Guardianship Office provides the following free leaflets:

- Enduring Powers of Attorney
- Making an application
- Duties of a receiver
- Handbook for receivers
- Fees
- Information for nursing homes, hospitals and other carers
- Handling the affairs of people suffering from mental disorder

The Public Guardianship Office also provides the following free forms:

- EP1 Notice of intention to register
- EP2 Application for registration
- EP3 General form of application
- EP4 Application for search
- Objections to registration of an enduring power of attorney

They do not provide the form you need for the enduring power of attorney. You must buy this from stationers who supply legal forms or some solicitors' firms.

To search for the registration of an enduring power of attorney, contact the Public Guardianship Office to obtain an EP4 search form.

Can relatives sign consent forms about a person's care and treatment?

Relatives should not sign consent forms on behalf of adult relatives who lack capacity or cannot express their wishes. These consent forms are not legally effective.

The medical team may ask friends and family what the person would have wanted. The Courts consider the views of relatives important when they reflect what the person would have decided themselves. Advance directives and living wills are ways of ensuring that a person's wishes are known.

In most cases an adult may not be treated without his or her consent. It is unlawful and unethical to treat a person who does not agree to treatment when they understand the treatment and the result of not accepting care and treatment.

The law assumes that a person understands the treatment and the consequences of any decisions until there is proof that they do not understand. An exception to this is treatment under the Mental Health Act of 1983. In order to be capable of giving consent, an individual must understand:

- the treatment or procedure being offered;
- the purpose of the proposed benefit of the treatment; and
- the possible results of agreeing to and refusing the treatment and care that is being offered.

Professionals should record fully all assessments of a person's ability to make decisions about care and treatment in the person's medical notes. When an adult lacks the ability to consent to medical treatment, no other person can consent to or refuse medical treatment on the individual's behalf.

However, in emergencies when the procedure or treatment is in the best interests of the person, the treatment will be lawful even though the person has not consented.

In simple treatment decisions the doctor, care providers, patient (where possible), their family and friends can agree treatment.

The Courts may require cases involving serious treatments to be brought before the Courts for individual review.

Such treatments include withdrawal of artificial hydration and nutrition from persons in a permanent vegetative state.

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treatment will be lawful even though the person has not consented. In simple treatment decisions the doctor, care providers, patient (where possible), their family and friends can agree treatment.

The Courts may require cases involving serious treatments to be brought before the Courts for individual review. Such treatments include withdrawal of artificial hydration and nutrition from persons in a permanent vegetative state.

Who can "section" a person?

Sections of the Mental Health Act 1983 in England and Wales set out procedures for admitting people to hospital for assessment or treatment of mental disorders. The person's nearest relative or an approved social worker can apply for admission to hospital under Sections 2, 3 and 4 of the Mental Health Act 1983.

Other sections of the Mental Health Act 1983 provide for admission and detention of people by doctors and nurses and police officers. The specific situation determines who should make the application and when.

Should you consider having a person admitted to a mental hospital?

Under Section 2 of the Mental Health Act 1983 (England and Wales), a person's nearest relative or an approved social worker may apply to have that person admitted to hospital for ASSESSMENT when: a person is diagnosed as suffering from mental disorder which meets the criteria for being kept in hospital for assessment, and it is in the interests of the person's health or safety; or it is for the protection of other people.

Two registered medical doctors must provide opinions and support the application. A person can also be admitted for treatment, as an emergency admission, or with the support of the police or a nurse.

The information in this section has been written by the Health Division, RadcliffesLeBrasseur Solicitors, 5 Great College Street, Westminster, London SW1P 3SJ. Phone: 020 7222 7040.

Access to records and making complaints

When should I contact my Councillor or Member of Parliament?

Please remember that your local Councillor or your Member of Parliament may be helpful in resolving the issue of your dissatisfaction.

Contact your local Councillor through your local authority about matters having to do with social services. You may write a letter describing your situation and telling the Councillor how you would like to see the matter resolved. Or, you may make an appointment at their surgery and speak with them. It is a good idea to have copies of letters relating to your complaint for them to review. You may want to let the councillor know what is happening at local level during a complaint investigation.

Contact your MP to let him or her know what you think about national issues or when you are dissatisfied with the result of the investigation by your local council and Councillor.

You can write to your MP at The House of Commons, Westminster, SW1P 0AA, or phone 020 7219 3000. The House of Commons answerphone in your MP's office should give you the phone and fax number of the MP's surgery, and the hours it is open

Access to your records

The law requires local government and health care providers to allow you to see your records, or send copies of them to you. They are also required to ensure that their records are accurate. The procedures you must go through to see your records depend upon the organisation.

In criminal investigations, or if seeing your records may harm you, they may also refuse to allow you to see your own records. Many people find it difficult or

confusing to understand official documents or records. The organisation must have a person present who can answer your questions about the records. Local authorities may have up to 40 days to provide access to records from the date you write asking to see the records.

Health care providers vary in what you must do to see your records. Sometimes, you only need to phone and ask to see the records. In other circumstances, you or your representative may need to have witnesses sign a form before you have access to the records.

Special rules guide people acting on behalf of others who need help in managing their affairs. If you ask for a photocopy, you will probably have to pay a fee.

The fee covers the cost of the paper, copying machine, and for the work involved in copying and filing your records. If you ask for copies after seeing your records, you may wait up to 40 days before receiving them.

Who can see a person's records?

Central or local government organisations may refuse to let someone see or have copies of personal records:

- from health care professionals
- if the information might harm the person in a physical or mental way
- relating to another individual mentioned in the records
- to close family members or friends of the client
- to other people receiving services, or
- held with others (e.g. minutes of meetings), if they do not have the others' consent.

They may share access to records of another person when the person who has been receiving their services provides written and witnessed consent. Special guidance relates to people acting on behalf of others in a protective role.

May social services share your confidential information?

Social services are under an obligation to keep confidential the information they receive about a person. However, a breach of confidence can be justified if it is to prevent illegality, 'gross immorality', or conduct contrary to public policy. Further, disclosure may be justified if it is to enable another body such as the local authority to assist in the making of an assessment as to needs and care.

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Can I comment about my local or health care services?

Your service provider appreciates letters of praise when you are pleased with their performance. You may be unhappy about what the council or health care provider have decided about your needs, what you must pay, your care plan, or services arranged by your local or health care service provider. You should ask to have your situation reviewed.

Local and health care providers should provide information about how to make and follow through a complaint. Each authority has a customer service officer or complaint officer who is responsible for investigating complaints.

You must make a complaint within 12 months of realising that you can make a complaint about your dissatisfaction. However, some hospitals require you to complain within six months of the event.

Keep copies of all letters and forms you send and receive from the authorities. Take notes of meetings and conversations. Ask for copies of minutes of meetings that you attend.

Also, keep a diary of your conversations with your service providers relating to the complaint.

Send copies of all letters, minutes, and notes related to the complaint to all relevant parties when making a formal complaint or appeal. Authorities are required to let you see your records when you write asking to see them.

They may not let you see notes or reports that may cause you harm when you read them. However, they can insist upon a notice of 40 days before allowing you to see the records.

If you are unhappy with some aspect of care in a residential care or nursing home, speak with the manager or matron. If your complaint is not handled to your satisfaction, contact the home's inspection unit to make a complaint. Tell the organisations that have arranged your placement if you have a complaint about care. They may help you in dealing with it.

What are the stages of making a complaint?

Stage one: When things first seem to be going wrong, telephone your care manager, a member of staff, the provider of your local authority care, or the customer service/complaints officer.

It is best for your service provider to make you happy with their services or decisions as quickly as possible. They want to fix things at the first, or informal stage. This stage is less costly and time consuming, and a friendly way to sort things. Discuss your view of the situation.

If the complaint is a health care provider, contact your local community health council for support. They must respond within 10 working days of knowing that you are not happy. They should also enclose a leaflet describing the local complaints procedure and contact details with their written response.

Stage two: If the informal discussion fails to get you anywhere, you can put your complaint in writing to the director of social services or chief executive of the health organisation.

They must send you a letter saying they have received your formal complaint within 10 working days. Social services then have up to 3 months to investigate and respond to complex complaints. They generally they should provide a response within 28 days of your complaint.

Matters relating to children

If you are a child making the complaint, or are making a complaint on behalf of a child, the deadlines are different. In these situations, the officer is required to respond to your complaint within 28 days.

In either situation, complaint officers must appoint an advocate or independent representative. In addition, you may also request the assistance of an advocate to help you by writing letters or attending meetings.

If you are unhappy with the result of their investigation, you may request stage 3 of the complaint procedure, an independent review of the investigation.

What can I do if I am unhappy with the investigation of my complaint?

If you are not happy with the result of the investigation of your complaint, you can ask that a panel reviews the decision. You must ask for the review within 28 days of the date on the letter reporting the decision of the first investigation.

Write to the chief executive of the organisation that you are complaining about to ask for an independent review. The chief executive will call a person who decides if there should be an investigation.

This person, known as a convener, may not agree that there should be an investigation. This convener may decide that there needs to be more discussion with the people you are complaining about, or for other reasons. If the convener agrees that an independent

review panel is necessary, you will receive a letter confirming this. The independent review panel will consist of at least three people. The chairman will not be an employee or director of the organisation involved in your complaint.

Preparing for the independent review

When you are getting ready for the meeting, put copies of all letters and notes in the order they happened. Make copies of all of the documents. Send a folder with one set of copies to the chairman of the panel in advance.

Also, include a letter telling the panel what you would like them to decide, and why.

It is a good idea to send your statement with a set of copies to the other panel members before the meeting.

The organisation that you are complaining about may only send information that supports their side of the complaint to panel.

If you do not send documents to the panel in advance of the meeting, the panel may come to the meeting not knowing your side of the complaint. The information that you send to the panel before the meeting may be the only way they have to know your side of the complaint before you meet them. You may have an advocate, friend, or a representative attend the meeting with you or go and speak on your behalf.

The Independent Review Procedure

If your complaint is with more than one organisation, you may need to make separate complaint with each service provider. It is possible that all people involved in the complaint will agree to meet resolve the complaints.

The convener may insist upon this before agreeing to an independent review. Social services departments have different review procedures than health authorities. Also, each community around the country has different procedures.

The agenda for the meetings vary regionally and organisationally. In some situations, you may be given a specific time to speak and answer questions.

In other settings, you may be given a time the meeting will begin with no schedule of when you or your witness(es) may be allowed to give evidence. Whilst offering you the opportunity to bring witnesses along, they may refuse to allow the witness to give testimony at the meeting.

The timing of the response of the independent review panel may range from one week for a social services review to more than one month for a health service review. People running independent review panels may tape the meetings. They may charge you as much as £45 for a copy of the tapes.

A local government monitoring officer has a duty to report any council proposal or decision that is, or could be, in contravention of the law.

They must also report actions or decisions appearing to be matters of maladministration or injustice for the Ombudsman to investigate. If you are not happy with the results of your independent review, you can write to the Ombudsman.

The Ombudsman

You can take the matter to the local government or health service ombudsman if you feel there has been a case of maladministration. Faults in the way the complaint has been handled are referred to as maladministration. Faults can include:

- neglect of duties
- discrimination
- unjustified delay, or
- failure to abide by or to have proper procedures.

The organisation that you complained about must send you information about how to ask for an Ombudsman's investigation. An Ombudsman's investigation can take years. The department that has

been investigated does not need to follow the Ombudsman's suggestions. The Ombudsman's power only extends to evaluating the way the authority investigated the complaint, not the merits of the complaint itself. Your last option is to ask a court to judicially review the authority's action or inaction.

Helpful organisations

Action on Elder Abuse

Phone: 0808 808 8141 (M - F 10.00 - 16.30)

Age Concern England

Free factsheets, and advice about issues including community care, benefits, and legal matters. Local branches may provide day centres, respite care, benefit advice, advocacy and/or handyman services.

Information line: 0808 808 6060 - (M, T 09.30 - 13.00)

Factsheet: 0800 00 99 66 - (7 days, 07.00 -19.00)

Alzheimer's Society

Helpline: 0845 300 0336 - (M-F 08.30 - 18.30)

Attention Deficit Disorder

A support group and help line for parents of children with hyperactivity and attention deficit disorders.

Support Line Phone: 01373 826 045

Benefits Agency offices are now called **social security offices**. The offices still deal with benefits.

Carers UK campaigns on behalf of carers.

CarersLine: 0808 808 7777

(M-F 10.00 - 12.00, 14.00 - 16.00)

Charity Search Helps older people to find charities that can provide grants to individuals.

Phone: 0117 982 4060 (M-F 10.00 - 16.00)

Community Legal Services provide information in English, Welsh, Bengali, Cantonese, Gujarati, Urdu.

Directory of advice providers: 0845 608 1122

Text Phone: 0845 609 6677

Contact a Family provides support to parent carers. Helpline: 0808 808 3555 (M-F 10.00 - 16.00)

Counsel & Care

provides information and casework about all aspects of services and benefits for older people.

Advice Line: 0845 300 7585

(M - F 10.00 - 12.30; 14.00 - 16.00)

Disability Advocacy Network

Phone: 020 8980 2200

Disability Benefits helpline

Department for Work & Pensions benefits information
Phone: 0800 88 22 00 (M-F 08.30 - 18.30; Sat. 09.00 - 13.00)

Disability Law Service

Phone: 020 7791 9800 - (M-F 10.30 - 13.00; 14.30 - 17.00)

Disabled Living Foundation

Phone: 0845 130 9177 - (M-F 10.00 - 16.00)

Eric - Information to help young people with bladder problems - Phone: 0117 960 3060 (M-F 10.00 - 16.00)

Health Service Ombudsman

Phone: 020 7217 4051

Henry Spink Foundation provides severely disabled children and their families with a comprehensive information resource - Phone: 020 7388 9843

Home Improvement Trust

Help to arrange funding for people over 60 years of age or younger with severe disabilities to help arrange and fund property repairs, improvements, and adaptations.

Phone: 0115 934 9511 (M - F 09.00 - 17.00)

Homeshare arranges for older or disabled people to remain in their homes by finding people to live in and provide care support.

Phone: 020 7378 6644

The Independent Living (1993) Fund (ILF)

Phone: 0115 9428191

Irritable Bowel Syndrome (IBS) Network

Phone: 01543 492 192 (M-F 18.00 - 20.00; Sat. 10.00 - 12.00)

Law Centres are in Yellow Pages under Legal Services.

Local Authorities, City Councils, Metropolitan or Borough Councils, and Unitary Authorities are listed in Yellow Pages under Local government. The operator at the main number should be able to direct your call to social services.

Local Government Ombudsmen

Adviceline: 0845 602 1983 (M-F 09.00 - 16.00)

- London boroughs north of the river Thames (including Essex, Kent, Richmond, Surrey, Suffolk, and East & West Sussex)
Mr. Tony Redmond - Phone: 020 7915 3210
- Harrow and London Boroughs south of the river Thames, Coventry, Lancaster, York, and the rest of England not included in the areas of Mrs. Thomas
Mr Jerry R White - Phone: 024 7669 5999

- The West midlands (except Coventry city), Cheshire, Derbyshire, Lincolnshire, Nottinghamshire, Shropshire, Staffordshire and the north of England (except Lancaster and York):

Mrs. Patricia A Thomas - Phone 01904 663200

Contact your **MP** at the House of Commons, London, SW1P 0AA, or phone 020 7219 3000.

Mencap provides information services to fulfill the lives of people with learning disabilities.

Helpline : 0808 808 1111 (Mon. - Fri. 10.00 - 16.00)

Mind - The Mental Health Charity provides information and advice services related to mental health issues - Infoline: 0345 660 163 (M-F 09.15-16.45)

NHS Direct provides information about: the NHS and care services; illnesses and disabilities; benefits; documents and procedures associated with health and social care services - Phone: 0845 4647

National Centre for Independent Living

They publish information about direct payments and hiring personal assistants as well as details of local support. Phone: 020 7587 1663

Nursing Homes Fees Agency provides information on obtaining and paying for all types of care.

Phone: 0800 99 88 33

Parkinson's Disease Association

Helpline: 0808 800 0303 - (M-F 09.30-17.30)

Patients Association

Helpline: 020 8423 8999 (M-F 10.00-15.00)

The Princess Royal Trust for Carers provides carer support at centres throughout the country with projects for young carers.

Phone: 020 7480 7788

Public Guardianship Office and Court of Protection

Archway Tower, 2 Junction Road, London N19 5SZ

Enduring powers of attorney

helpline: 0845 330 2963 (Mon. - Fri. 8.00 - 18.00)

Relatives and Residents Association

Phone: 020 7916 6055 - (M-F 10.00 - 12.30; 13.30 - 17.00)

Royal National Institute for the Blind UK

Helpline: 0845-766 99 99 - (M-F 09.00 - 17.00)

Textphone: Typetalk 0800-51 51 52

Royal National Institute for Deaf People

Phone: 020 7296 8000 - Textphone: 020 7296 8001

The Stroke Association

Helpline: 0845 303 3100



*Westminster Health Care
are delighted to support Caring Matters.*

*As a leading independent provider of long-term care,
our prevailing purpose is to bring*

*Hope, Healing and Sanctuary
for the Mind, Body and Spirit*

through the care services we deliver to our Residents

For further information, please contact us as below:

Westminster Health Care (UK) Ltd.
Westminster House, Randalls Way, Leatherhead, Surrey, KT22 7TZ
Phone: 01372 860 300 Fax: 01372 860 333 e-mail: info@whc.co.uk
Website: www.whc.co.uk

Caring Matters is a national charity that works to empower people involved with long-term care.

People need the right information at the right time to make the best care decisions.

We provide information about procedures, rights, responsibilities, and resources related to long-term care, to help:

- people needing long-term care
- their loved ones and carers
- care managers, social workers, and home helpers
- doctors, nurses, and speech, occupational and physio-therapists, and
- information and advice providers.

We appreciate comments, suggestions, or donations that would help us to improve the quality and range of our services.

Long-term care is like a black ice road.

Even while you're alert
you don't know what lies ahead
until you're nearly hurt.

Each bend and turn on the slick ice
with the sun's blinding glare
delays getting where you need to go
– just like providing care.

We have a way to help you
get beyond the black ice roads.
Caring Matters can guide you
as your care path unfolds.

Come to us when you need to know
just where to turn and when.
We'll help you see the road ahead
before you reach the bend.

Ruth Windsor 01/01/01



Patrons Lord Morris of Manchester AO, QSO • Lord Rix Kt, CBE, DL • Roger Jefcoate CBE, HonMA • Harry Cayton OBE, BA, BPhil, Dip Anth
Chairman Lady Nourse • **Founder and Chief Executive** Ruth Windsor
Trustees Simon Kenton • Anne Munn • Philip Spiers ATII

Caring Matters, 132 Gloucester Place, London NW1 6DT. Phone: 020 7402 2702. E-mail: info@caring-matters.org.uk
www.caring-matters.org.uk

National Advisory Panel

- Caroline Bielanska LLB (Hons) • Alan Bland • Clive Bowman FRCP, Geratologist, University of Bristol • David Brownlee, Age Concern Scotland
- Andrew Cozens, Association of Directors of Social Services • Carole Cochrane, Princess Royal Trust for Carers • Ann Darnbrough, Director, National Information Forum • Simon Foster • Martin Green, Chief Executive, Counsel & Care • Pauline Hamblin • Ian Purvis, Age Concern England
- Professor Malcolm Johnson, Director, International Institute on Health & Ageing • Andrew Kent, Director of Development, NHS Primary Care Group Alliance • Simon Kenton • Simon Lovestone, Institute of Psychiatry • Brian McGinnis OBE, Mencap • Anne Munn NDD, MICFM
- Margaret Richards LLB • Relatives & Residents Association • Sheila Roy • Craig Ward, Alzheimer's Society • Sandra Williams, Age Concern Coventry.