

- Provide a pot for night-time use. Use luminous tapes to mark the route to the toilet. Always take them before they go to bed and, if it prevents a wet bed, take them during the night.
- Keep a check on their diet. If they are not eating enough roughage they may develop constipation, which can lead to a blocked bowel and leaking diarrhoea. Increase vegetables, fruits and wholegrain cereals.
- Try to reduce embarrassment by adopting a matter-of-fact approach, directing their attention to the task of cleaning and washing and avoiding any recriminations.
- To protect your furniture use washable covers over dustbin liners. Beds can be protected by using a plastic sheet between a draw sheet (a sheet folded in half and tucked in across the bed).
- Special pads and pants are available from chemist shops or through health authorities (ask your district nurse). Some local authorities provide a laundry service (see *Practical help* on p.46).
- Ask to see a continence adviser who could help with further advice on suitable pads/pants and individual solutions.

DELUSIONS AND HALLUCINATIONS

Delusions are ideas that are imaginary, but seem very real to the person experiencing them. Someone experiencing delusions may believe that there are some people who want to kill or harm them, or that objects that are simply mislaid or hidden have been stolen, even by members of the family.

Someone experiencing hallucinations sees or hears things that aren't actually there. They may wake to see figures at the foot of the bed, or hear dead relatives talking to them.

Possible solutions

Both delusions and hallucinations are imaginary, but they can give rise to genuine feelings of anxiety or panic, and should be taken seriously. It is important to realise that not everyone finds hallucinations unpleasant or distressing, but it's wise to be prepared in case they do.

When the person with dementia is experiencing a delusion or hallucination, don't argue with them or tell them they are mistaken. Remember they are outside the person's control so becoming angry or impatient with them will not help. If the delusion concerns a missing object, for example, try to find it, rather than deny it has been stolen. If the person is distressed by a hallucination explain that you understand what they are feeling, but also that other people cannot see or hear what frightens them. Try to comfort them, perhaps by putting an arm round them or holding their hand, and try to distract their attention on to something real around them.

If the person you are caring for begins to suffer from distressing delusions or hallucinations, you should see your GP. It could be that medication is causing the problem, or the problem itself might respond to drugs.



SEXUAL RELATIONSHIPS

The sexual relationship in any relationship is very private and personal and not something that many carers can talk about easily. While dementia does not necessarily affect sexual relationships, the person's attitude to lovemaking may alter. They may not respond to affectionate gestures that you make or they may lose interest altogether. They may simply forget about it.

You may find that you lose interest yourself because of the stresses and tiredness brought on by caring for your loved-one. You may find it difficult to make love with a person whose personality has changed so much.

Occasionally, a person with dementia may become more demanding.

Possible solutions

There is no simple solution to a complex and sensitive issue such as this. If you find that your sexual relationship is becoming a problem, you should try and talk to an understanding person about it. There are counsellors trained to talk to people about such problems. Your GP should be able to put you in touch with someone.

INAPPROPRIATE SEXUAL BEHAVIOUR



In some cases a person with dementia may exhibit inappropriate sexual behaviour, such as undressing in public, exposing themselves, or aimlessly fondling their genitals. In fact, such behaviour is unlikely to be sexual at all. Appearing naked in the sitting room may simply be the

result of forgetting they should get dressed, or of losing their way to the bathroom. A man found 'exposing' himself, may only be trying to urinate in an unsuitable place. One carer's mother seen 'exposing' herself in the street had wandered out in the cold in her nightdress and pulled it up around her shoulders to try and keep warm.

Possible solutions

Behaviours such as these can cause severe embarrassment to carers, but your understanding of the problem – and explaining it to others – should lessen your embarrassment. If the person touches their genitals in public, don't make a scene, but try to discourage them gently. If they appear naked, or start undressing themselves, remove them calmly to another room. It may be worth checking that clothing is not uncomfortably tight, or fastenings broken. In those rare cases where people complain and police or other officials become involved a truthful explanation usually receives a sympathetic response. Whatever happens, do not worry that this kind of sexual action will lead to harmful sexual behaviour – it won't.

VIOLENCE AND AGGRESSION

The person with dementia's frustration or over-reaction to a difficult situation may occasionally erupt into aggression and violence. When it is directed at the carer it is especially distressing.

The person may also show anger or aggression towards other family members. Several carers



mentioned a particular problem with teenage children, whom people with dementia often seem to resent, perhaps because they represent youthfulness and hope that they know is over for them.

Possible solutions

Whatever you do, do not respond to aggression with aggression. It will only make matters worse. Instead, stay calm yourself – count to 100 if need be – and try to distract their attention. Find out what brings on the reaction – frustration at a difficult task, a certain person's presence, rushing to be ready on time – and try to avoid it in future.

If episodes of violence and aggression become frequent, you should talk to your GP about medication that may help.

FAILURE TO RECOGNISE PEOPLE

A person with dementia often lives in the past. If a man thinks of himself as still in his forties, it is not surprising that he denies he is married to someone in her sixties or seventies or that he thinks his 40-year-old daughter is his wife.

Possible solutions

Keeping out large photographs of family occasions through the years, so that the person with dementia sees that he (or she) has also grown older has helped some families. Understanding what is happening can relieve the distress carers feel at rejection.



LEGAL MATTERS

As the dementia progresses, the person with dementia may no longer be able to handle their own financial and other affairs. But help is available from a range of professionals and services. This chapter explains some legal matters and refers you to sources of information.





On a day-to-day level, this may not cause any problems. It is relatively easy for you to take over routine tasks such as paying bills, collecting the person's pension, paying the rent and so on. You can get a form from the Jobcentre Plus, which allows you to collect their pension or benefits. It is important to obtain advice about Enduring Power of Attorney and the Court of Protection at the earliest possible stage (see below). Understanding bank managers and others who require the person with dementia's signature on documents may allow you to sign on their behalf. It would be a good idea to get a joint bank account if you have not already got one.

However, it is not wise to allow the situation to drift along. If the person's affairs are complicated – for example, if they own a business or property – you should get expert legal advice as soon as possible about any possible problems before they arise. For example, spouses who own their home jointly may find that they are unable to sell it or, if they do, that they are not entitled to all the proceeds of the sale.

English law provides two ways for a person's affairs to be taken over. The first is Enduring Power of Attorney. The second is the Court of Protection.

Enduring Power of Attorney

This gives one person the legal right to manage another's financial affairs. It can be given only when the person creating the Enduring Power of Attorney is

deemed mentally capable. The Enduring Power of Attorney Act 1985 makes it possible to appoint an attorney who has the power to act after the person becomes mentally incapable. The person still has to be mentally capable when creating this power, so it may become common practice for people to appoint an attorney when making their will. It is important, if possible, to establish the wishes of the person with dementia while they are still able to express them. This will ensure you know what they would want when they are no longer able to tell you.

The Court of Protection

This court can appoint a receiver – a member of the family, a solicitor or the Public Guardianship Office – to administer a person’s financial affairs if that person has become mentally incapable. The appointment of a receiver takes approximately eight weeks from when the application form is lodged with the court to the receipt of the order by the parties concerned.

However, in a case where the assets involved are under the threshold the court can authorise a Short Order if it does not think that the appointment of a receiver is necessary. A Short Order authorises an individual to deal with a person’s estate.

If there are financial matters that need urgent attention, parties may apply to the Court for an interim or emergency order enabling financial matters to be managed pending the appointment of a receiver.

Mental Capacity Act 2005

The Mental Capacity Act 2005 allows a person to appoint a Lasting Power of Attorney (LPA) to act on their behalf if they should lose capacity in the future. This is like the current Enduring Power of Attorney (EPA), but the Act also allows people to let an attorney make health and welfare decisions.

The Act also provides for a system of court appointed deputies to replace the current system of receivership in the Court of Protection. Deputies will be able to take decisions on welfare, health care and financial matters as authorised by the Court. They will only be appointed if the Court cannot make a one-off decision to resolve the issues.

The Act also creates a new Court of Protection which will have jurisdiction relating to the whole Act and will be the final arbiter for capacity matters. It will have its own procedures and nominated judges. A new Office of the Public Guardian will be responsible for registering the authority for LPAs and deputies. It will supervise deputies appointed by the Court and provide information to help the Court make decisions.

The Mental Capacity Act 2005 will be implemented in April 2007.

Information on current and future legislation on decision making, including Enduring Power of Attorney and applications for appointing a receiver, are

available through the Public Guardianship Office. Their address is Archway Tower, 2 Junction Road, London N19 5SZ and they can be reached by phoning 0845 330 2900 or visiting their website at www.publictrust.gov.uk. There is a specific helpline on telephone number 0845 330 2963.

You should go to your Citizen's Advice Bureau, Neighbourhood Law Centre or family solicitor for advice on these matters.

USEFUL ORGANISATIONS

Some of these organisations publish their own material on dementia and caring for people at home. Some run groups for carers. These are national organisations and many can provide details of local groups.

AGE CONCERN ENGLAND

Astral House
1268 London Road
London SW16 4ER
Information Line:
0800 00 99 66
www.ageconcern.org.uk

AGE CONCERN SCOTLAND

Causewayside House
160 Causewayside
Edinburgh EH9 1PR
Phone: 0845 125 9732
www.ageconcernscotland.org.uk

AGE CONCERN NORTHERN IRELAND

3 Lower Crescent
Belfast BT7 1NR
Phone: 028 9032 5055

AGE CONCERN CYMRU

Units 13–14
Neptune Court
Vanguard Way
Cardiff CF24 5PJ
Phone: 029 2043 1566
www.accymru.org.uk

ALZHEIMER'S SOCIETY

Gordon House
10 Greencoat Place
London SW1P 1PH
Phone: 020 7306 0606
Helpline: 0845 300 0336
Email: enquiries@alzheimers.org.uk
www.alzheimers.org.uk

ALZHEIMER'S SCOTLAND

22 Drumsheugh Gardens
Edinburgh EH3 7RN
Phone: 0131 243 1453
Dementia Helpline:
0808 808 3000
Email: alzheimers@alzscot.org
www.alzscot.org

BENEFIT ENQUIRY LINE

(for people with disabilities and their carers)
Freephone: 0800 88 22 00
Monday to Friday
8.30 am–6.30 pm; Saturday
9.00 am–1.00 pm

BRITISH ASSOCIATION OF OCCUPATIONAL THERAPY

106–114 Borough High Street
Southwark
London SE1 1LB
Phone: 020 7357 6480
www.cot.co.uk

CARERS UK

20/25 Glasshouse Yard
London EC1A 4JT
Phone: 020 7490 8818
www.carersuk.org.uk

CITIZENS ADVICE BUREAU

See under National Association of Citizens Advice Bureaux

COUNSEL AND CARE

Twyman House
16 Bonny Street
London NW1 9PG

Phone: 020 7241 8555
Advice on residential care and benefits:
45 300 7585

www.counselandcare.org.uk

CROSSROADS ASSOCIATION

10 Regent Place
Rugby
Warwickshire CV21 2PN
Phone: 0845 450 0350
www.crossroads.org.uk

DEMENTIA RELIEF TRUST

6 Camden High Street
London NW1 0SH
Phone: 020 7874 7210

DISABLED LIVING FOUNDATION

380–384 Harrow Road
London W9 2HU
Phone: 020 7289 6111
Helpline: 0845 130 9177
www.dlf.org.uk

ELDERLY ACCOMMODATION COUNSEL

3rd Floor
89 Albert Embankment
London SE1 7PT
Helpline: 020 7820 1343
www.patient.co.uk

HEALTH EDUCATION BOARD FOR SCOTLAND

Woodburn House
Canaan Lane
Edinburgh EH10 4SG
Phone: 0131 536 5500
www.healthscotland.com

HEALTH PROMOTION DIVISION, NATIONAL ASSEMBLY FOR WALES

Ffynnon-las
Tŷ Glas Avenue
Llanishen
Cardiff CF14 5EZ
Phone: 029 2075 2222
www.patient.co.uk

HELP THE AGED ENGLAND

207–221 Pentonville Road
London N1 9UZ
Phone: 020 7278 1114
SeniorLine: 0808 800 6565
Care Fees Advice Service: 0500 767476
www.helptheaged.org.uk

HELP THE AGED SCOTLAND

11 Granton Square
Edinburgh EH5 1HX
Phone: 0131 551 6331
SeniorLine: 0808 800 6565
www.helptheaged.org.uk

HELP THE AGED WALES

12 Cathedral Road
Cardiff CF11 9LJ
Phone: 029 2034 6550
Seniorline: 0808 800 6565
www.helptheaged.org.uk

HELP THE AGED NORTHERN IRELAND

Ascot House
Shaftesbury Square
Belfast BT2 7DB
Phone: 028 9023 0666
Seniorline: 0808 800 6565
www.helptheaged.org.uk

MIND (NATIONAL ASSOCIATION FOR MENTAL HEALTH)

Granta House
15–19 Broadway
London E15 4BQ

Phone: 020 8519 2122

Infoline: 08457 660 163

**Publications:
020 8221 9666**

www.mind.org.uk

NATIONAL ASSOCIATION OF CITIZENS ADVICE BUREAUX

Myddleton House
115–123 Pentonville Road
London N1 9LZ

Phone: 020 7833 2181

www.citizensadvice.org.uk

NATIONAL CENTRE FOR INDEPENDENT LIVING

4th Floor
Hampton House
Albert Embankment
London SE1 7TJ

Phone: 020 7587 1663

Fax: 020 7582 2469

Text: 020 7587 1177

Email: ncil@ncil.org.uk

www.ncil.org.uk

NHS DIRECT

Phone: 0845 46 47

www.nhsdirect.nhs.uk

THE PRINCESS ROYAL TRUST FOR CARERS

142 Minories
London EC3N 1LB

Phone: 020 7480 7788

Email: info@carers.org

www.carers.org

RADAR

12 City Forum
250 City Road
London EC1V 8AF

Phone: 020 7250 3222

Minicom: 020 7250 4119

(Mon–Fri 9.00 am–5.00 pm)

Email: radar@radar.org.uk

www.radar.org.uk

THE RELATIVES AND RESIDENTS ASSOCIATION (FOR ENGLAND & WALES)

24 The Ivories
Northampton Street
London N1 2HY

Phone: 020 7359 8148

Email: relres@totalise.co.uk

www.relres.org.uk

LOCAL INFORMATION

NAMES, TELEPHONE NUMBERS AND ADDRESSES FOR EASY REFERENCE

YOUR DOCTOR

PRACTICE NURSE

DISTRICT NURSE

HEALTH VISITOR

HOSPITAL SERVICES

LOCAL AUTHORITY SOCIAL WORKER

MEALS-ON-WHEELS

HOME HELPS

VOLUNTARY ORGANISATIONS

LOCAL CARERS' GROUP

OPTICIAN

Who cares?



'Who cares? gives information in a realistic, yet sensitive manner.'

Alzheimer's Society



'We found the book very understanding of the pressures placed on the carer.'

Age Concern (England)



'The book is excellent and full of practical ways to help carers.'

Help the Aged



Department of Health

DH Publications Orderline

PO Box 777

London SE1 6XH

Tel: 08701 555 455

Fax: 01623 724 524

E-mail: dh@prolog.uk.com



08700 102 870 - Textphone (for minicom users)

for the hard of hearing 8am to 6pm Monday

to Friday

www.dh.gov.uk

Design: Persona Grata

Cover illustration: Debbie Lush

31276 9p 45k Oct 05 (BEL) 271352