

Frequently asked legal questions

The Alzheimer's Society receives around 1,000 enquiries a year about the law relating to dementia. This information sheet gives answers to some of the most common types of questions.

Social services want to put my wife in a home - what are my rights as a carer?

The social services department has a duty of care for vulnerable adults living in its area. It has to assess the needs of these adults and provide services and/or equipment to meet any assessed needs. Therefore, if social services believe that a person's care needs can no longer be met at home, they can place that person in an environment where their care needs can be met, such as a care home.

If the social workers and any doctors involved consider that someone with dementia can no longer be cared for at home, they will first try to persuade them to go into a care home. However, some people with dementia don't realise that they have a problem and are reluctant to leave their home. Striking a balance between their safety, the safety of others and their freedom is not easy. As a last resort, the social workers and doctors can force a person to go into hospital. This is commonly known as 'sectioning' the person, as it uses powers under a section of the Mental Health Act 1983 for England and Wales. The terms of the section allow a person at risk to be taken to a place of safety without their consent. This is an uncommon step, which is not taken lightly. It may, however, be necessary in extreme situations.

If a carer or concerned friend/relative wants to prevent a person being placed in a home, they should talk to their social worker about their concerns. There are ways to help manage the care of a person at home, including arranging for paid carers to visit up to three times a day to provide help with washing, dressing and cooking. Social services must act in the best interests of the person with dementia. It is, therefore, worth discussing whether the person's best interests are being served by placing them in a care home.

The GP won't tell me my husband's diagnosis - can he be made to do so?

The Data Protection Act 1998 covers medical records, and medical professionals often quote it when families ask to see a person's medical notes or ask to be kept informed about their care. Medical professionals are within their rights to quote this piece of legislation. However, it could be argued that it is in the patient's best interests for the information to be made available so that the people who are involved in their care are well informed and able to act in the person's best interests.

If the medical team still refuses to comply, the friends/family can complain to the primary care trust.

Social services want to put my dad in the only home available, which is 30 miles away, where it will be very difficult for my mum to visit him. There are homes nearer but there are no vacancies - what are our rights?

It depends on the person with dementia's situation. If he or she is in hospital and has had their needs assessed, the local authority could be fined for every day that the person occupies a hospital bed. In this case, the local authority will be keen to have the person discharged as soon as possible (this is called 'delayed discharge'). Therefore, they might not want to wait until one of the more desirable homes becomes available.

If the person is living at home, the family could suggest that a package of care at home (paid carers coming in) be put in place until a place at the home of choice becomes available.

It may also depend upon how much money the person has. If they have more than the upper threshold for assets and savings (see information sheet *Benefit rates and savings/income thresholds*) they will be paying for care themselves. However, if they don't the local authority will be contributing to their care and there will be a limit to how much it will contribute. It may be that the only home within the local authority's budget is the one 30 miles away.

In any case, the local authority has a legal duty to meet the needs of the person with dementia and to act in his or her best interests. The family could argue that the person has a need to be near to their family. If this is written into the care plan, the local authority must try to meet this need. Case law states that social services are not allowed to put someone in a home further away simply because it is the cheapest (see examples in 'Further reading' below).

Can someone be taken off a Section 117 or be denied continuing care if they have been under a Section 117 or receiving continuing care for some time?

There are over 100 parts of the Mental Health Act; these are called Sections. People can be placed under certain Sections of the act, depending on their situation. For example, many people with dementia are placed under Section 3, which gives medical professionals authority to detain the person in hospital for treatment.

Section 117 applies to people who have been detained under certain Sections, including Section 3. It deals with aftercare arrangements and ensures that the person receives free appropriate aftercare when they are discharged from hospital. If, however, an assessment is carried out six months after discharge and the person is assessed as no longer needing these services, they may be taken off the Section 117. However, case law demonstrates that extreme caution must be taken when making this decision (see examples in 'Further reading').

The case may be similar with continuing care - a person may be assessed as having severe healthcare needs when they leave hospital and be assessed as qualifying for NHS funded care. However, with the right medication and attention some of their problems may become less serious, even though people do not 'recover' from dementia.

To challenge a decision in either case, the person should make a complaint to the primary care trust and highlight the fact that dementia is a degenerative illness that will not improve with time.

Why is/isn't the person I care for being Sectioned while they are in hospital?

Practice varies regarding people with dementia who are admitted to hospital. Health professionals have to treat every case individually.

Carers' feelings about their friend/relative going into hospital and staying there for assessment also vary. Some feel that there is a stigma attached to being Sectioned (placed under a Section of the Mental Health Act). Others feel that it is wrong to detain a person with dementia in hospital if they have not been Sectioned, as the person might not have capacity to consent to their stay in hospital as a willing patient (see Bournwood case below).

If a person is under Section, their nearest relative can object to the Section and have it reviewed at a tribunal if they feel that the person is being kept in hospital unnecessarily. If the person is considered to be a 'voluntary' patient, it is more difficult to arrange an independent review.

Problems can arise when people with dementia are unable to communicate their wishes. Hospital staff may interpret their behaviour as indicating a willingness to remain in hospital. Carers may feel that the opposite is true and that the person does not try to leave the hospital because they are too confused about where they are.

The Bournwood case, which concluded at the European court of human rights in October 2004, ruled that a man with autism had had his human rights contravened when he was kept in hospital for four months without being Sectioned. During this time, his foster family had wanted to take him home but had been told that they were not able to do so. As far as the hospital was concerned, the man was a voluntary patient. However, it would have been impossible, the family argued, for the man to communicate his wishes to either stay or to go home.

If you are concerned about someone who is in hospital, you can contact the patient advice and liaison service (PALS) based at the hospital. PALS provide information, advice and support to help patients, families and their carers. They can liaise with staff to resolve issues with hospital care or discharge.

What are the rights of a carer who feels that they cannot care any longer?

While we may feel morally responsible for the care of family and friends, no individual has legal responsibility for the care of another adult. The local authority and the social services are legally responsible for care they have assessed a person as needing.

If a carer feels that they can no longer care for someone with dementia but they know that the person would be at risk without their support, they should contact social services and tell them how the situation has changed. If the person is in hospital and the staff are talking about an imminent discharge, the carer must make it clear that they feel unable to care for the person with dementia at home. Hospital staff would be acting negligently if they discharged the person with dementia in this situation without a full investigation.

If the person with dementia is living at home with the carer, the carer should talk to their social worker about what extra help might be available to help them cope at home or to give them respite care. In some cases, residential care may be the best option both for the individual and their carer. The carer can look at homes in the area and choose an appropriate environment for the person with dementia but the social worker will have to be satisfied that the home meets the person's needs. Social services will also carry out a financial assessment (see the Society's information sheet *When does the local authority pay for care?*)

Social services must be satisfied that any vulnerable adult is living in an environment in which they can be adequately cared for. If the main carer says that they can no longer care, no pressure should be put on them to change their mind.

Why is it necessary for us to arrange an enduring power of attorney (EPA) now?

The law states that anybody incapable of managing their own finances comes under the authority of the Court of Protection (see 'Further reading'). The Court of Protection ensures that such people have either an EPA or a receiver to act on their behalf. If someone loses the capacity to look after their money and a relative or friend needs to take over, an EPA is more straightforward than receivership and the person can choose who they would like to look after their money (see information sheet *Enduring power of attorney and receivership*). The law insists upon this to protect vulnerable people from being exploited. While the majority of people are honest and would not defraud someone with dementia, there are a minority who would, even within families.

Another reason why an EPA is important is that bank accounts are generally set up to operate on the condition that the person or persons in whose name the account is held is capable of managing that bank account. For example, if an account is held in joint names but one of the account holders becomes unable to understand or manage the account, the bank could freeze all transactions and only release funds once someone produces either an EPA or receivership order for the person who has lost capacity. This means that the person with capacity is also unable to get access to the funds in the account.

I have been told that I have to wait 12 weeks for my aunt to be assessed by social services. Is this right?

Currently there is no set timescale in which assessments should be carried out. However, if someone is refused an assessment, experiences an unacceptable delay, or finds that their needs are not met by the care plan drawn up as a result of the assessment, they can complain to social services.

If the person's needs are urgent, social services can provide appropriate services before the assessment is carried out. Social services need to be informed of this situation.

Provision of services must never be based on ability to pay. If someone with dementia is assessed as needing a service, it must be provided. Arrangements for payment should be made separately.

Further reading

Case in which it was demonstrated that eligibility criteria cannot be tailored due to shortage of money from the local authority: *Regina v Gloucestershire County Council, ex parte Barry*

Regarding Section 117 and removal of Section for people with dementia, see *R v Watson ex parte Richmond*

The Court of Protection operates under statutory guidance deriving from Part VII of the Mental Health Act and the Enduring Powers of Attorney Act 1985.

Useful contacts

The Public Guardianship Officer

Archway Tower
9 Junction Road
London N19 5SZ

Literature and application forms: 0845 330 2900 (weekdays from 9am to 5pm)
Enduring power of attorney helpline: 0845 330 2963 (weekdays from 9am to 5pm)

Email: custserv@guardianship.gov.uk

The Department of Health

Richmond House
79 Whitehall
London SW1A 2NL

Customer service centre: 020 7210 4850 (weekdays from 9am to 5pm)
Email dhmail@dh.gsi.gov.uk

NHS Direct

24 hour service providing help for people who are feeling ill and information about local patient advice and liaison services.

Telephone: 0845 46 47

Alzheimer's Society legal and welfare helpline

Can provide information on a range of legal and welfare issues

Telephone: 0845 300 0336

Information sheet 475

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