



Dementia: making decisions

A practical guide for family members, partners and friends with powers of attorney, guardianship or deputyship





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Alzheimer Scotland

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About this guide

This practical guide aims to help family members, partners and friends who have been appointed to make decisions on behalf of a person with dementia either as an attorney, guardian (Scotland) or deputy (England and Wales). Other people involved in caring for a person with dementia may also find it useful.

Rights of the person with dementia

People with dementia have the same rights as anyone else in society but the nature of their illness means that they often have difficulty protecting their own rights and interests.

In Scotland, the relevant legislation is the Adults with Incapacity (Scotland) Act 2000; for England and Wales it is the Mental Capacity Act 2005. These laws comply with the UK Human Rights Act (1998) and the European Convention on Human Rights.

- *This guide sets out how using the principles in these laws can help you to reach decisions which support the rights of the person you care for.*

Your rights as a proxy decision-maker

You have a right to have your powers recognised and decisions respected by statutory authorities and others you deal with on behalf of the person you care for, so long as you are following the principles and rules set out in law.

Help to overcome barriers

Dementia is a disabling illness which affects the person's ability to make decisions for themselves. This is an additional challenge for carers. Family members whose experience informed this guide told of difficulties in dealing with bureaucracy, professional differences and family conflicts.

- *This guide aims to help you find a practical way through these difficulties by using the key principles or rules.*

A signpost

This guide cannot tell you whether a decision is right or wrong – circumstances will differ and each individual is unique. It does not provide answers to complex situations or deal with ethical dilemmas.

- *This guide does provide a way to disentangle some of the difficulties by applying the principles. The guide signposts you to further information and where to find specialist help.*

This guide does not constitute legal advice and it does not replace the Codes of Practice which you should also follow (see Resource list).

Unsure of becoming a decision maker?

If you are not yet a guardian/deputy or attorney but are caring for someone with dementia you might find this guide helpful. You will probably be supporting the person to make their own decisions and might soon need legal powers to take important welfare, health or financial decisions. Other guides have been written for family members, partners and friends on how to make an application for guardianship or deputyship, and about Powers of Attorney (see Further information page 57).

- **Find out all you can but 'Do it'**

Do it – find out as much as you can about dementia and what is involved – know that it takes more time than you ever imagined – but you have the satisfaction that you are doing the best you can for the person you love. Attorney, Scotland

Part One

1 About making decisions

As adults, we all have the right to make our own decisions. The law assumes that we can all do so unless there is good reason and evidence to suggest otherwise.

What influences you when you make a decision?

Making decisions for ourselves is not always easy at the best of times. How we each make decisions can be influenced by: those around us; our past experiences; our emotional state at the time; stress; our culture and beliefs; our approach to risk taking; economic and other pressures.

Presented with similar circumstances, many of us will make different decisions because we give greater weight to some factors than to others. We often seek the advice of family, friends or colleagues. Many of us seek expert help at some time or other in our lives. Sometimes we make hasty, impulsive or unusual decisions but this does not mean we lack capacity.

The law states that a person is not to be treated as unable to make a decision just because he or she makes an unusual or unwise decision. Nor is someone to be automatically considered to lack capacity because they have a diagnosis of dementia and may need support in making decisions.

For all of these reasons, deciding when and how to use your powers to make decisions on behalf of the person with dementia is not easy. Part Two of this guide sets out the principles or rules that will help you and a checklist of questions to ask yourself when considering what to do.

Proxy decision-makers involved in this study advised:

Remember that you are not making decisions for yourself – you have to think about what the person would want themselves, which may not be what you would choose.



2 How dementia affects decision-making

Dementia is the umbrella term for a number of conditions which cause damage to the brain cells. The most common form is Alzheimer's disease which has a gradual progression. The next most common type is vascular dementia which has a step-like progression. About one in four people with Parkinson's disease also develop dementia. Short-term memory loss, disorientation and loss of concentration are common symptoms.

There are other less common types of dementia such as Lewy Body dementia and Frontal Temporal dementias (including Picks Disease) which affect the parts of the brain which control social behaviour.

Whatever type of dementia the person has, it eventually affects their ability to absorb, understand and remember information; to weigh up options and make reasoned judgements; and protect their own interests.

Ability to make decisions is not 'all or nothing'

The law states that decision-making is not 'all or nothing'. This means that an individual with dementia should be given all the help and support they need before anyone concludes that they cannot act in their own interests or make their own decisions. It also means recognising which decisions the person can make and which they cannot make – for example they may be able to make some more simple decisions, but not others.

The law also recognises that a person with mental disorder has the same right to make unwise decisions as anyone else. This means that you should not impose your own judgement about the choices the person makes, for example, how they wish to spend their money or their style of dress.

Early stages

People at the early stages of the illness will continue to have the ability to make decisions for themselves. For many people, the

progression is slow which means they can make their own decisions for some time but may need additional help.

For example, someone in the early stages may be quite capable of carrying out their normal everyday tasks and travel to familiar places alone, but forget how to use money and need support with that.

'To begin with, my wife gave me the correct bus fare, but now I have a bus pass so that makes travelling easier and I don't feel like a child.' Person with dementia, Scotland

'I told my friends, "I have this illness called Alzheimer's and I forget things – I need you to ring me up to remind me when to get ready for the club". I get more upset when I go to make a cup of coffee and find it's cold because I forgot to boil the water.'

Person with dementia, Scotland

As the illness progresses

As the illness progresses, the person may be able to make some choices, for example, about household matters, or where they would like to go on holiday, but need someone else to make the arrangements (see section 6 on supporting the person to make decisions).

'I wanted my sister who cares for me to have a break but I refused respite in a care home – she is my attorney and asked about other options - social work came up with the idea of me staying with a family at the seaside – they arranged this for me and I had a lovely time'. Person with dementia, Scotland

'I could manage the microwave but not the cooker - I'm happy with having hot meals that way - I kept letting things boil dry.'

Person with dementia, Germany

If the person makes a decision about something with which you disagree or think is unusual, you need to decide whether or not they are at undue risk or if it really matters and why.

Sometimes people with dementia become unaware of the potential dangers involved in the risks they are taking and this presents dilemmas about whether or not to intervene and stop them. It will be a matter then for carers to weigh up the degree of risk against the benefits for the person. The application of the rules is essential here too and some practical examples are given later in the guide.

If the person's behaviour becomes challenging and they are putting themselves or you at risk of harm, you should ask for specialist dementia advice either through your GP or direct to the health care professional, usually a specialist nurse or consultant, who already has the care of the person.

Local authorities have a responsibility to assess community care and support needs of both the person with dementia and their carer. Social workers may be particularly helpful in discussing the implications of your concerns for the care of the person with dementia.

'I had no idea I could ask for an OT to visit my mum's home to make it safer for her – now I don't have to worry about the gas being left on or the water overflowing as they fitted gadgets to turn them off automatically – they also came up with ideas to help her do things more easily for herself.'

Later stages

In the later stages of the illness, the person's ability to understand and communicate is likely to be very limited. Decisions you need to take at this time can be helped by knowing in advance, from past conversations or an advance care plan, what the person would have wanted for themselves. It is important to have this sensitive conversation with the person and professional health care staff while the person is still able to communicate.

If this is no longer possible, it will help to bring into focus your knowledge about what the person would have wanted for themselves and to discuss this with others who know the person well. Speak with others whom you trust to support you, and gather the information

you need about palliative care to ensure the best possible care and treatment is provided.

For further information see:

Alzheimer Scotland: Letting go without giving up: continuing to care for the person with dementia (2005).

End stage dementia: the dementia journey. www.alzscot.org/pages/policy/end-stage-dementia.hmt

Alzheimer Society: Fact Sheet 'Advance Decisions' and 'Advance Care Planning'

3 About the law and decision-making

In Scotland the Adults with Incapacity (Scotland) Act 2000 was introduced to protect individuals (aged 16 and over) who lack capacity to make some or all decisions, or take necessary action for themselves, and to support their families and others in managing and safeguarding the individual's welfare and finances. In England and Wales the equivalent law (for individuals aged 16 and over) is called the Mental Capacity Act 2005.

Although the provisions in both laws differ, the principles or rules for proxy decision-makers are similar (although Lasting Powers of Attorney in England and Wales only apply to people aged 18 or over). These are set out in the Codes of Practice (see Resource list). It is important to have a copy of the relevant code of practice as a point of reference or to have access to it on the internet as the law requires you to follow the rules set out in the Code (unless you can show very good evidence as to why you have acted differently in the specific circumstances).

Top priority - know the principles/rules

In England, the Mental Capacity Act 2005 was introduced five years after the Adults with Incapacity (Scotland) Act 2000 and built on the principles in the Scottish law.

The principles aim to help you, and others with duties under the law, to balance the rights of the person to self-determination with their right to security and protection. This guide has integrated the principles from both Acts because, together, they will support you to reach decisions that are in the best interests of the person you care for. By following the principles you will also keep within the law.

Quick guide to the principles:

Principles to consider before making a decision for the person:

- Assume capacity unless there is evidence to suggest otherwise.
- Don't assume the person lacks capacity just because they make an unwise decision.
- Provide practical support to the person to make their own decision before treating them as lacking capacity to do so.

Any decision you make on behalf of the person who lacks capacity must:

- benefit the person/ be in their best interests
- take account of their past and present wishes, values and beliefs
- take account of the views of relevant others – family, professionals
- restrict the person’s freedom as little as possible to meet their needs
- encourage the person to use their existing skills and to develop new skills.

The principles to be observed are contained in:
Part 1 s1 of the Adults with Incapacity Act; and in
Part 1 s1 of the Mental Capacity Act.

Part Two of this guide looks in more detail at the principles and their application to making welfare, healthcare and financial decisions.

Dementia and the right to self-determination

It is a basic human right that an individual with a diagnosis of dementia must be assumed to have capacity in relation to a specific decision at the time the decision needs to be made, unless there is good reason to suggest otherwise. This is common law in Scotland and the first principle of the Mental Capacity Act for England and Wales.

The law recognises that someone with impaired capacity may be capable of making some decisions and not others – capacity is not all or nothing. For example, they may have the capacity to appoint a family member to take care of their financial affairs as their attorney but lack the capacity to make complex decisions about their assets for themselves.

You have a ‘duty of care’

Under common law, you have a duty of care for the person whose financial or welfare matters you are managing. This means that you have to act with skill and care in exercising the powers you have been granted and to seek help if you feel at all out of your depth. There are various places you can turn to for help, depending on the problem in hand. If you are unsure who to contact for advice, in

Scotland you can call Alzheimer Scotland Freephone 24hr Dementia Helpline 0808 808 3000 or in England and Wales contact the Alzheimer Society Helpline: 0845 300 0336, open 8.30 am - 6.30 pm Monday to Friday.

Decisions you are not allowed to make

There are certain decisions attorneys and guardians/deputies are not allowed to make. You cannot:

- admit someone to a psychiatric hospital or
- prevent or allow the person to marry/have sexual relations *
- request a decree for a divorce for the person
- make a will for the person
- vote on behalf of the person

* If you are concerned about potential abuse you should report this to the person's healthcare professional or social worker.

Making decisions - liabilities

You are in a position of trust and have a legal duty to act carefully and reasonably in exercising your responsibilities as a guardian, deputy or attorney. You are unlikely to be held liable for any decision you make if something goes wrong and you can show that:

- you acted within your authority and within the limits of the powers granted
- the decision was made in good faith and was reasonable
- the decision was made in the best interests of the person and you had regard for the principles.

If you wilfully neglect the person you will be guilty of an offence and subject to criminal law.

4 Starting out – using your powers

Starting to use your powers - let others know

It is important to have a clear understanding of the powers you have been granted and to inform others, ideally before you need to use them e.g. care manager, doctor, bank manager. It will save time and assure others if you have copies of your guardianship/deputyship certificate or a registered power of attorney document to show them.

When we asked carers who took part in this study to check their powers, many were quite surprised, for example, to see that they either did or did not have: the power to make health care decisions; to access confidential information; to make a regular donation to the person's favourite charity; or to give presents to family members and friends.

Some carers assumed that because they have certain powers they have the right to take over all decision making from the person. But remember, capacity to make decisions is not 'all or nothing' and you have to apply the principles in relation to specific decisions in hand (see Part Two).

Powers of attorney

The person you care for has appointed you and possibly others with you to take the responsibility of making decisions on their behalf when they are no longer able. It is you (and any other appointees) who have to decide when the person lacks capacity. They may have stipulated that you need to get an independent medical assessment of their capacity before you can act.

If you have been granted powers **jointly** with another person you must always make all decisions together. If you disagree then the decision cannot be made.

If the power of attorney document appointed you and one or more individuals on the basis that decisions can be made '**jointly or severally**' this means that you can either act together or independently. Alternatively the power of attorney document/s may

have specified a division of labour, for example, one person to deal with finances and the other to deal with health and welfare.

Whatever arrangement has been made, it is important that you collaborate, using the principles as a guide.

Guardianship/deputyship powers

As a guardian or deputy you will have been appointed by the court. There will have been an independent assessment that the person you are acting for lacks capacity to make certain decisions or types of decision for themselves. You will have been granted specific decision-making powers in relation to the person's finances or welfare and health or all of these.

Carers report that making an application and going to court is a stressful process. Sometimes the stress is increased because they feel that they are letting the person down, going against their wishes, for example, to remain at home. It can be an emotional time for everyone involved. If you have used the principles, you can be sure that the decision is in the best interests of the person and that your action is necessary for their care and protection.

You may have been **appointed jointly** with someone else to share decision-making or you may have a designated division of labour with one person appointed to make welfare decisions and the other to make financial decisions. There may be a substitute. If this is the case, you will need to co-operate using the principles as your guide.

5 About capacity and incapacity

Earlier in this guide, it is explained that everyone is assumed to have capacity, including people with a mental disorder such as dementia, unless there is evidence to suggest this may not be the case. This is common law in Scotland. It is a principle of the Mental Capacity Act for England and Wales. The Adults with Incapacity (Scotland) Act and Mental Capacity Act are the same in recognising that the individual may have capacity to make some decisions but not others.

Incapacity is not 'all or nothing'

You have a duty to support the person to make their own decisions as far as possible and only use your powers when the person lacks the capacity to do so for themselves.

Capacity is the ability to:

- understand information relevant to a decision or action
- understand and weigh up the options
- understand the possible consequences of taking or not taking a particular decision
- make a decision
- retain information and remember the decision
- communicate the decision.

Sometimes it is difficult to know if someone is capable of making an informed decision. We might think that someone is unable to understand information about their circumstances and the decisions which may need to be taken, but how do we know?

Understanding 'understanding'

There are two strands to 'understanding'

- having a grasp of the facts
- having the ability to weigh up the options and foresee different consequences of one choice over another.

In assessing if the person you care for is able to weigh up information to make a decision, you need to be clear about the decision or decisions to be made and what the options might be.

The next step is to consider how to put across the information for the person. How you give the information will affect the person's ability to understand.

Helping the person who forgets

The person with dementia may have severe short-term memory loss, but this does not automatically mean that they lack capacity to make a decision.

They may be able to understand the situation and make a decision but not able to remember all the relevant information. Aids such as voice recorders or simple written notes could be used to support the person's memory and record their responses.

You may need to talk to the person several times to go over the information to see if their response is consistent (even though they may not remember that you asked them before). If the response is consistent, this may be taken as the person having sufficient capacity to understand.

Lack of memory does not equal lack of capacity

Is the person susceptible to 'undue pressure'?

The person may be susceptible to the pressures and influences of others seeking to take advantage of them for their own gain. For example, the person may allow a distant family member to live in the house for free and use their pension to live on.

When assessing if the person has capacity to make a decision in their own interests, it will be important to determine whether they are being influenced by such undue pressure from others. In circumstances where you have good reason to suspect that the

person you are acting for may be subject to abuse, you should seek help straight away from a healthcare or social work professional; contact the Office of the Public Guardian where money or property is involved, and consider contacting the police.

Assessing capacity

You need to weigh up all the reasons you have for believing that the person can't make a decision with all the reasons indicating they can make a decision. This will help you decide if they have capacity based on the basis of the 'balance of probabilities' (Code of Practice, Mental Capacity Act).

But first, there are a number of ways you can help the person to understand their circumstances and involve them as far as possible in reaching decisions affecting their life.

6 First principles: supporting the person with dementia to make decisions

The law aims to protect people who lack capacity to make particular decisions, but also to support their involvement in making decisions about their lives as far as they are able to do so.

The first three principles or rules set out earlier in this guide are all concerned with considering whether the person has capacity to make a specific decision at a particular time or not. You must follow these principles or rules before you make a decision or action on their behalf.

First principles

1. You should not treat the person as being unable to make a decision unless all practical steps to help him/her to do so have been taken, without success.
2. The person has a right to be supported to make their own decisions and communicate their decisions before it is assumed they lack capacity.
3. It should not be assumed the person lacks capacity simply because their decision/s may seem unusual or unwise.

The person you care for has a right to support to help them overcome their difficulties and to communicate their views and wishes in whatever way is appropriate to their needs.

Here are some ways to help them:

- Always communicate relevant information calmly and simply, taking time; use props (e.g. photos); give information about choices in a balanced way.

- Use simple language and broad terms to explain; keep it simple without going into detail. It may help to break up the information into small sections and to give them extra time to think it over.
- Find the time when the person is most alert; eliminate distracting noise (TV, radio); take one decision at a time; try to avoid tiring the person; be prepared to abandon the first attempt and try other times.
- Consider whether the person you care for has any other conditions which affect their concentration and ability to communicate, such as poor hearing or diminished eyesight which may be treatable. These could influence their communication and ability to be involved in decision-making.
- Remember that the person's ability to think about a decision will be affected if they are suffering pain or discomfort, or if they are taking medication which causes drowsiness, or have a short-term illness. Consider delaying the decision until the person is feeling better, is physically comfortable and more mentally receptive.
- People with dementia may have fluctuations in their mental abilities over a day or several days. They may have spells of feeling anxious and agitated. So finding the right time to involve them in making decisions is very important. It is well known that emotional distress is a barrier to making decisions.
- Consider suggesting the person talks with another family member or friend.
- Use publications and DVDs which have been produced to help people who need support to make decisions and for those who provide support (see Resource list).
- Older people with dementia will have a long history, both personal and medical, which will influence how they respond to their present circumstances. Recognising this in how you approach discussion of the decision to be made will be helpful.

- The person's culture, for example, their beliefs, family traditions and gender, may have an effect on everyday decision-making.
- If the decision is complex e.g. an important decision about their health or social care, consider involving professionals to help the person make the decision or assess their capacity.

If the person keeps behaving or making decisions which place them at risk of harm or exploitation but they don't understand the consequences, it would be reasonable to conclude they are losing or have lost capacity. It would be reasonable for you to intervene and use your powers or duty of care to provide them with the care and protection needed.

10 hints on supporting decision-making

- Keep it simple
- Be clear about the decision in hand
- Be objective about the options
- Use props e.g. photos
- Take time – when the person is alert, pain free, calm
- Quiet place – no distractions
- Help the person express what is important to them now
- Help the person communicate e.g. body language
- Remember what influenced their decision-making in the past
- Ask a friend/advocate/professional who knows the person for their help

A practical guide which is helpful to families as well as professionals everywhere is: *Communication and assessing capacity: a guide for social work and health care staff* (see Resource list page 59).

Office of the Public Guardian/Ministry of Justice booklets:
www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

Part Two

7 Principles to follow when the person lacks capacity to decide

The previous section covered the three principles or rules you need to follow to support the person to make their own decisions as far as possible. This section is about how you can make good decisions for someone who is unable to make decisions in their own interest.

Making decisions - best practice principles

Principle 1

Every decision or action you take on behalf of the person who lacks capacity must be for the person's benefit/ in their best interests.

Principle 2

You must not restrict the person's freedom any more than is necessary to achieve the benefit you want for them.

Principle 3

You must take account of the wishes, feelings, values and beliefs of the person, and give them every assistance to help them communicate.

Principle 4

You should consult with others concerned with the person's well being as far as possible – family members, friends, professionals involved in their care and anyone named by the person.

Principle 5

Encourage the person to use their existing abilities and skills and develop new skills.

Why the principles are important

The principles are, in effect, rules that, you, the proxy decision-maker, must follow. They are there to support the rights of the person you care for and they are also there to empower you to decide or act on behalf of the person with dementia. Others are required to recognise the rules and your authority to act on them.

Using the principles or rules to help you reach a decision

Using the principles as a way of reaching decisions for someone who is struggling or unable to do so for themselves is very helpful. They help you to think through decisions that seem (and may be) straightforward as well as those that are more challenging.

Applying the rules in complex situations will help you untangle the threads and highlight what else you need to do before going ahead with a decision.

Using the rules can also help you to be more objective if you are feeling stressed. It will help you to pause and take time if you are feeling pressured to make a decision.

The study found that many carers were not aware of the principles, although most used a 'common sense' approach which, in effect, mirrored what the law required. This worked well in everyday situations when matters were straightforward.

Making tough decisions in challenging situations

Carers said that if they had known the principles it would have helped them manage challenging situations where they were in conflict with family members, professionals or the person with dementia.

Those carers who did know their rights as proxy decision-makers sometimes found themselves up against health and social work staff and care home managers who were unaware of the law and found themselves having to quote the appropriate section of the legislation or Code of Practice (see Resource list).

If you are challenged, you should have no problem justifying that you have acted in good faith provided you can demonstrate that you have used the principles to support your decision.

8 Principles into practice

Principle 1: Every decision or action you take on behalf of the person who lacks capacity must be for the person's benefit/ in their best interests.

Any action or decision you propose to make for the person must be to promote their wellbeing and provide the best outcome for them. You must be clear about why the decision or action needs to be taken and why the option you have chosen will benefit them more than other options. At the same time, the decision or action might benefit you or other family members. While that is acceptable, it must not be the main reason for your decision and it must be the least restrictive option for the person.

For example: It is an important part of John's week to go out to meet friends in town and attend appointments on his own but he is finding using buses too difficult (numbers don't mean anything to him any more). His attorney needs to decide, in discussion with John, what the best solution would be to enable him to maintain his independence. His attorney would need to consider the options such as: using dial-a-cab; driving John himself; finding a volunteer driver; getting a friend to collect him. John might decide that using dial-a-cab will help retain his sense of independence but it will cost more than the bus. The attorney might think that if he bought a car with John's money this would mean he could take John out and about a lot more and could use the car for himself. It would not be acceptable to buy a car with John's funds if it was mainly for the use of the attorney. This option would also make John more dependent. Weighing up the options with John will need to be done as objectively as possible, giving precedence to his views and wishes.

Conflicts of interest

The principles should help you to work through any potential conflict of interests and weigh up the options using the 'balance sheet' approach (see page 30). If not, you may need to seek independent advice (see Where to get help, page 57).

Principle 2: You must not restrict the person's freedom any more than is necessary to achieve the benefit you want for them.

You must be sure that any action or decision you are considering must be the least restrictive of the person's freedom in order to achieve the benefit you want for them.

When the person's needs change, it is advisable to ask their social worker or care manager (if there is one) for an assessment or review. An assessment of the person's capacity in relation to any specific decisions may be necessary. (See section 11, page 37, Making welfare decisions)

For example: When the person becomes unable to wash and dress themselves as the illness progresses, the least restrictive option may be to bring care and support services into the home, rather than moving the person to a care home. You may also need specialist dementia advice on how to support the person, for example, if the person becomes incontinent or if their behaviour becomes hard for you to cope with.

Principle 3: You must take account of the wishes, feelings, values and beliefs of the person, and give them every assistance to help them communicate.

In deciding if an action or decision is needed, and what that should be, the laws say that you must take account of the person's present and past wishes and feelings. This will include considering their values and beliefs as these will have influenced how they made decisions in the past as well as now, if they were able to do so.

This means listening carefully to the person and helping them to express their views and feelings about the matter in hand. You may need to give some thought as to how best to communicate the options. For example, you might try using memory aids, or prompts such as photographs or non-verbal communication (see section 6, pages 18-20, First principles).

Where a change of service is recommended, such as day care, an advance visit would be an important way to help the person to understand and respond to what is on offer.

Advance Decisions/Directions

In advance of losing capacity, the person may have put their wishes for their future care and treatment in a written statement. If so, you should try and follow this where possible. You must follow any such instructions the person made in a Power of Attorney providing it is in their best interests.

If the person lives in England and Wales then, under the Mental Capacity Act, if the person has written a valid Advance Decision to refuse treatment, this must be followed, irrespective of whether it is in the person's best interests. In Scotland, the law is less certain about the status of advance decisions but there would need to be good reason for ignoring an advance decision statement since it is an expression of the person's wishes. An advance decision made in England, Wales and Scotland does not allow any action to be carried out which would be against the law.

Where communication is very difficult

Even when communication with the person has become a real problem, you can still follow this principle by taking the person's past wishes into account. As their attorney, deputy or guardian, you will probably know the person well and be familiar with their preferences and the sorts of decisions they would have made in the past. You will know how they feel about certain matters such as 'flu vaccinations' or whether they have always been a 'loner' or enjoy the company of a group. If not, you should ask others close to the person about their past preferences.

To follow this principle does not mean that you have to do exactly what the person would have wanted, but that you should respect their views and be clear about the reasons for doing otherwise. Satisfying the person's wishes might be unrealistic or unsafe. A positive response might be to find out what is especially important to them about their particular desire and finding a way

to help it happen. People's wishes are often quite modest and not hard to meet.

Principle 4: You should consult with others concerned with the person's wellbeing as far as possible

In deciding if an action or decision is to be made and what that should be, you should, as far as possible, take account of the views of anyone else who is actively concerned for the wellbeing of the person. Others include close family members and friends; the primary carer (if it is not yourself); other attorneys if the person has appointed them; the person's care manager (if there is one); other health or social care professionals/staff involved in their care or treatment; the person's accountant or financial adviser if it's a money matter.

The purpose is to consult and get other opinions on what needs to be done. At the end of the day it's your decision, but you are obliged to talk to them – even if you know they will disagree. If anyone thinks you are abusing your powers they have recourse to the complaints system set out in the relevant Codes of Practice.

What is 'reasonable and practicable'?

The law says that you are only expected to consult as far as it is 'reasonable and practicable' to do so. This phrase is not defined in the Code of Practice and a common sense approach will mean taking into account how easy or difficult it is to consult with others.

For example: if a relative has not taken any interest in the person or not been in contact for some considerable time, it would not be reasonable to expect you to consult them; or if the person has moved abroad and is hard to contact it may not be practical to involve them in anything but major decisions you know they will be concerned about.

Principle 5: Encourage the person to use their existing abilities skills and develop new skills

You are expected to encourage the person you care for to do as much for themselves as possible, but in a gentle way. This is to help them

to maintain their abilities for as long as possible. Often it is quicker to take over completely but this may result in the person feeling helpless; they may give up trying and become apathetic, or angry. If the person is being cared for in a care home or by carers coming into the house, you should talk with the staff in charge about the importance of taking an 'enabling' approach. Specialist dementia care staff will know about the benefits of supporting the person in this way and should be able to help you as well as other staff in providing the right sort of care and support.

Keeping up old pleasures and doing new things

For example: *People who have always baked enjoy the chance to do so in a safe environment. Try maintaining activities that the person has always enjoyed, even if they are unable to do them as well as they used to e.g. playing bowls, gardening. Explain to friends how they can help.*

Creative minds

You may think that developing new skills or regaining old skills is out of the question for people with dementia. However, given the opportunity, they can surprise us with their creativity at a time when their mental functioning appears to be in decline. For example, joining a singing group and participation in art, photography or story telling are recognised as stimulating and life enhancing activities.

My support worker asked what I used to enjoy and I remembered I liked taking photos of the family way back. So now we take the camera out with us and I've managed to take some good shots.

Person with dementia, Scotland

Weighing up the principles - making decisions

Carers are often required to make decisions that are sensitive and contentious. You may have considered all the options and taken into account everyone's views and find that the course of action you want to take conflicts with the wishes of the person and recommendations of service providers. It is important to be as clear as possible with the person, and with others involved why you are making a particular decision.

Any decision or action must be for the benefit of the person and relate to their specific needs and circumstances. The information you have gathered from considering the other principles will help you reach a decision in the person's best interests.

The Making decisions' checklist, section 15 on page 47 will guide you.

You are only expected to do what is proportionate to the circumstances.

For example: if the person has accumulated funds in a current account, you can go ahead and move some to a higher interest bearing account without going through the whole process of consultation. But if you propose purchasing something major for the person that might require selling assets, it will be essential that you involve the person as far as possible as well as consulting with others. In Scotland and England it would be advisable to consult with the Office of the Public Guardian in the respective countries.

For example: for day to day decisions you don't need to consult widely but you do need to know about the person's likes and dislikes, to take account of their current views and feelings and ensure others who are providing care or support also have this information so they can act accordingly.

For example: He refuses to shave – but I remembered seeing photos of himself with a beard as a young man, so why not let him grow one again.

Depending on circumstances one principle might be seen as more important than another.

For example: the person has expressed a wish to go on holiday and stay in the same hotel that they have always enjoyed in the past but lacks the capacity to make any arrangements. The plan does not meet with the approval of all family members who think it is too expensive and that the person would enjoy just as much going somewhere nearer and cheaper instead. It will be important to give more weight to the wishes of the person, to respect their capacity to decide where they want to go and to fulfil their desire which will significantly enhance their quality of life. Clearly, to arrange the holiday the person wants will be in their best

interests and will outweigh the case for preserving money which may be the main concern of the other family members.

Write things down – a balance sheet approach

In weighing up the principles and deciding how to act in specific circumstances, you may find it helps to write down the person's views, the views of others, the benefits and disadvantages arising from the preferred options. This is what the Mental Capacity Act Code of Practice describes as a 'balance sheet approach'. A checklist is provided on page 47. It does not cover every circumstance or question but it will help you to assess what you need to do.

Consider the wishes of the person, balance these against their need for care and protection; consider how their quality of life can be improved emotionally and socially; listen to the recommendations and views of professionals, other family members and friends; act as an advocate; and make decisions.

9 Deciding when to use your powers

Even when you have tried everything to support the person to make their own decisions, it can still be difficult to know when to take over. The person with dementia may continue to express strong views but this does not mean that they have capacity.

When the person refuses help

It is distressing when the person you care for refuses services or other support that you know will help them. Sometimes, they may be adamant about being able to manage on their own, even when the situation is worsening by the day. They may put themselves at risk and refuse to co-operate. Typical examples are where the person has lost all sense of personal hygiene, forgets to eat and drink, lets strangers into the house, wanders outside in nightwear, bothers the neighbours at all hours, gets confused about the value of money.

The need for action

Any lack of action by you in the face of such resistance may lead to serious self-neglect of the person's physical and mental health or to your own health from the distress of dealing with the conflict.

By delaying action you may be doing the person a serious disservice. While waiting for risks to increase enough to require crisis intervention, the person's options may have been running out.

This is what happened in a case investigated by the Mental Welfare Commission in Scotland. You can read about this in a report called, 'With the best of intentions' (July 2010) which refers to 'Mrs I'.

Mrs I refused all help but was clearly deteriorating rapidly. But the risks were allowed to run high by family members with powers of attorney and health and social care professionals because they felt they would be infringing her rights if they forced her to move against her will. In the end things got so bad that she was compulsorily detained in hospital under the Mental Health Act. In hospital, she settled and enjoyed the care and company but unfortunately died shortly after.

This distressing situation could have been avoided if there had been a better understanding of capacity and dementia by health and social care staff, and proper assessments and reviews involving Mrs I and her attorneys. See Resource list, page 60.

Can a welfare attorney or guardian move the person against their will?

In Scotland

For welfare attorneys: The law in Scotland does not allow an attorney to move the person from their own home to a care home against their will, even though they lack capacity and you think that the move is necessary for their own benefit. (An exception would be if the power of attorney document specifically allows this).

To help resolve the dilemma you need to consider all of the principles: to consult with social work and ask for a review; to consider 'the least restrictive' option which might include helping the person to remain at home with an increase in care services to support them.

If admission to a care home becomes necessary, and the person continues to refuse to move, you will need additional powers. It would be advisable to request help and information from the person's local authority social worker or mental health officer. You may be advised to apply to the sheriff court for an order requesting specific powers allowing you to move the person against their will (this could be a Welfare Intervention Order, which allows a one-off decision or a Welfare Guardianship Order). You are entitled to free Civil Legal Aid to meet the costs or you can make the application yourself.

For further information see Resource list, page 59: Making an application for guardianship and intervention orders – a guide for carers, Scottish Government (2007).

For welfare guardians: If you already have welfare guardianship powers to decide where the person is to live and arrange care but you have not requested a power to take them there when they refuse to go, you will need to apply to the court for the specific power to allow

the move. (See Resource list page 59, Code of Practice for persons authorised to act under Intervention orders and Guardian. Adults with Incapacity (Scotland) Act 2000).

In England

For welfare attorneys: Under the Mental Capacity Act, a welfare attorney can remove someone to appropriate accommodation against their will provided that the move is not a 'deprivation of liberty'. As there is no legal definition of this, it is advisable to consult with social services in such circumstances.

For deputies: The Court of Protection may appoint a deputy with powers to move someone who lacks capacity and is resisting if it is in the person's best interests to do so.

Can I use my powers to restrict the person in other ways?

Anything you decide to do for the benefit of the person should always be proportionate and lead to outcomes that are the least restrictive of the rights and freedoms of the individual, providing they are in the person's best interests. The use of restraint must be the minimum necessary and for the minimum amount of time required to save the person from harming themselves or others.

My mum kept trying to get out of the car while I was driving her to the hospital. I had to use the child-safe lock or she would have had an awful accident. Carer, Scotland

Much will depend on the specific circumstances of the person you care for. For example, it is not always the case that a move to a care home will be more restrictive of the person's freedom than if they were to remain at home.

For example, a move to very sheltered housing or a care home for someone with limited mobility who lives in a top floor flat could improve the quality of the person's life, especially if they have been isolated and trapped in their own four walls.

Restricting the person with dementia for their own safety, knowing how easy it is for them to become lost, disorientated or at risk in their own homes, is of great concern for carers and those professionals seeking to support them. It is important to consider ways to reduce risks but, at the same time, enable the person to live as full a life as possible. Often involving the person's friends and other informal help in the local community can help to improve the person's enjoyment of life.

The Mental Welfare Commission for Scotland has a series of good practical guides on the use of restrictions e.g. locked doors, electronic surveillance, and covert medication (see Resource list, page 60).

'You know you have done all you can, there is no need for guilt, don't let it get in the way of the love which you can still give'
Carer, Berlin.

10 How to avoid or deal with conflicts

Let others know what you have in mind

Carers often report conflicts with other family members and professionals over decisions they want to take. It is good practice and in accordance with the principles to consult with others as far as practical. Let family members and others know what you are planning to do and get their views in advance. You or the care manager could call a care review meeting to try to resolve what is to be done.

Agreeing to disagree

Despite your best efforts, there may be times when disagreements cannot be overcome. In such cases, you should point out what your statutory duties are as an attorney, guardian/deputy. It will help if you can show that you:

- have applied the principles
- have balanced one principle against the other in a reasonable way (e.g. where the benefit/best interests principle outweighs the 'minimum intervention' principle)
- have taken into account the past and present wishes and feelings, values and beliefs of the person
- are aware of and have taken into account the views of others close to the person or involved with their care. You do not need to give more weight to one view over another or to follow the majority view where it is different from your own assessment of what needs to be done.

It is therefore very important that you keep some form of record e.g. a diary, particularly for major decisions and notes of meetings and discussions, letters, e-mails and significant phone calls.

If you are unable to persuade others to accept your judgement, you may wish to seek additional advice, for example, from the Public Guardian, a solicitor, health or social work staff, or an independent advocacy service, depending on the issue. If you are a guardian in Scotland, you will have a local authority supervisor or, if you are a deputy in England or Wales, you will have a supervisor appointed

by the Court of Protection to consult. If you can produce written advice from professionals, this may help to persuade others who are challenging your decision.

'Ultimately you may find that you simply have to insist, do not back down – you would be letting the person down if you were to give in for the sake of peace or gave up your powers in the face of opposition' Adults with Incapacity (Scotland) Act 2000, Code of Practice for persons authorised under Intervention Orders and Guardians.

11 Making welfare decisions

As a family member, partner or friend, you will know the person well and be very familiar with their chosen way of life, including the people, places and things that are important to them. It is also important to recognise the value of the person's existing relationships, particularly family, friends and others in the community and to help them to keep up their involvement.

You are probably the person best able to communicate with the person and to support them in making their own decisions, as far as possible. If their dementia has advanced beyond the point at which you are able to find out what they are feeling about a specific decision, an application of the principles will help to lead you in the right direction.

Meeting the changing needs of the person

Because of your close involvement with the person it is good to take a step back and try to gain an objective overview. It is helpful to get together on a planned basis with other people with decision-making powers (if there are any) and with anyone else closely involved or concerned about the care and wellbeing of the person.

Try to have a positive and effective relationship with professionals and service providers. This does not mean that you have to agree with their advice but that you should consider their recommendations carefully before deciding on a course of action.

Holding a review

You can hold a review meeting whenever you feel that circumstances are changing. The idea is to avoid having to act in a crisis. Changing circumstances may be due to the nature of the illness or other factors, including possible changes to your own situation, or that of others involved in the person's care.

If there is a local authority social worker, care manager or named health professional involved in the person's care, they should be able to assist with these meetings.

Checklist: is there a need for a review?

The following checklist is to help you think objectively about whether there is a need for a review or what else you might do. Remember – although you have responsibility for decision-making, you don't have to manage all on your own – you can be supported to make decisions too!

- What is the new/key decision that needs to be made about the person's welfare or care? Does the person have capacity to make the decision (with support if necessary)?
- Can the person be involved in the decision-making process even if they lack capacity to make the actual decision; who else needs to be involved?
- Check that the person seems well and happy in their current circumstances. If not, are there things that could be improved in some way? For example: reintroducing once familiar activities or friends; increasing or changing services.
- Assessing the person's home/accommodation for suitability to their needs – would aids and adaptations help; is it warm enough; can anything be done to reduce the risk of falls? (Falls are a major cause of admission to hospital and advice from an occupational therapist might be helpful).
- Is the person functioning as well as they might – for example, has their eyesight and hearing been tested recently; how are their feet? Is there a continence problem? Are they sleeping at night?
- Has the person adequate clothing?
- How is the person supplied with meals – is it the sort of food they enjoy? Are they able to cook for themselves; do they have any special dietary requirements?
- Is the person a member of a faith community or local congregation that they want to continue?

- Does the person have ongoing medical problems that need to be tackled?
- Is the person's home clean and well maintained?
- Does the person need a holiday?
- Does the person have regular contact with friends, family and others close to them?
- If the person is in residential care, are they being treated with dignity and respect? Is their freedom of movement restricted as little as possible? Are there appropriate activities in place? Is there a care programme appropriate to their needs?
- Your own needs – are you receiving the help and support you need in caring for the person? You have a right to an assessment.
- Can you anticipate changes and look ahead to future needs of the person?

Help to get the services you want for the person

Some carers in the study felt that reviews did not always lead to getting the services that would be most helpful. Often, a move to a care home was offered without the option of increasing the package of care to support the person in their own home. In other cases the generic services offered were so poor that they speeded up admission to a care home.

As a welfare guardian or attorney, you don't have to consent, for example, to any accommodation that you don't think is suitable for the person. If you are unhappy with an option you should discuss your concerns with the local authority care manager or social worker; suggest other options; consent to a temporary placement awaiting appropriate accommodation, or enhanced care at home. On the basis of the assessed needs of the person, you can insist on being offered a choice.

Find out about Self-directed Support – direct payments

Self Directed Support offers individuals real choice and control over their support. A supported person should be offered a choice of four options:

- receiving a direct payment
- choice of how the money for their support is spent
- allowing the local authority to choose on their behalf
- or a mix of the above three options.

If you have welfare guardianship or welfare powers of attorney you should be offered these choices on behalf of the person with dementia, and, following the principles, you should involve them as far as possible in decisions about the sort of support they would prefer.

Self Directed Support allows you to organise and plan care in ways that suit the particular circumstances of the person and to fit in with the help you are able to provide and other forms of support you already have – from family, friends and neighbours.

If managing a personal budget yourself is a bit daunting, it can also be managed by social services but you should be told how much money has been allocated and decide how it is spent (with reference to the person's assessed needs and the principles).

If a person has been assessed as requiring 24 hour care, it would be possible to ask for a direct payment to meet this need at home as an alternative to admission to a care home. This has been tried successfully for individuals and their families involved in a pilot service in Scotland.

For further information see Resource list, Scotland: page 61, 'Taking Charge' and for England, page 62, Dementia Choices.

12 Making healthcare decisions

Inform the person's doctor

If you have healthcare decision-making powers, you need to ensure that this information is on the person's medical record so that their doctor or other healthcare staff know you are the substitute decision-maker and have the authority to give/refuse consent to treatment for the person. It is a good idea for the persons' GP to have on file a copy of the certificate granting you powers; and you will need to make sure they have your up-to-date contact details including mobile phone number and e-mail address/s; and a note of whether you wish to be contacted at any time of the day or night.

The doctor should talk with you as if you are the patient. The doctor should explain the risks and benefits of treatment options. You will need to think what the person you are acting for would have wanted (not yourself).

For example: *One carer in the study was attorney for a relative who was a Jehovah's Witness and had specified that she did not want a blood transfusion, even if it was to save her life. This was stated in her power of attorney document. If this is stated in an Advance Directive in England and Wales it cannot be overturned.*

You might want to discuss with the doctor in advance: the types of treatment that you would be happy to agree to without the need to contact you first; and the circumstances in which you must be contacted before treatment is started, for example, surgery, resuscitation and end of life decisions; or where psychoactive medication is being considered.

If the person is in a care home

If the person is living in a care home, you need to make sure that information that you are the person's healthcare decision maker and your powers are noted on the person's medical file and other care records held by the home. The care home will also need your up-to-date contact details e.g. mobile phone number and e-mail address.

Going into hospital

If the person needs to be admitted to hospital in an emergency or as a planned admission, it is very important to ensure that your contact details go with them and are placed on the admission file.

NHS 24

You can also arrange for information that the person has a diagnosis of dementia and that you are their welfare attorney to be made accessible to NHS 24 on 'Special GP Notes'. You can ask the person's GP to arrange this. This will save time if you or the person with dementia needs to contact NHS 24 for help.

Consent to medication – your rights

Many carers in the study were concerned about the inappropriate prescribing of psychoactive drugs, which has been widely recognised as causing serious side effects for many people with dementia. Where carers had observed adverse effects on the person, they found it hard to get care home staff or the doctor to listen to them. They felt that their powers were disregarded or not understood.

If you experience a lack of regard for your status on this or any other welfare matter, you can seek advice from the Office of the Public Guardian (England and Wales), the Mental Welfare Commission (Scotland), a local advocacy agency or voluntary organisation such as the CAB or Alzheimer Scotland or Alzheimer's Society (England, Wales and N Ireland). If the problem persists, you can make a formal complaint.

Keep asking questions

If you have medical treatment decision-making powers you have a right to be fully involved in discussions about proposed treatments, to ask questions and be regarded as the substitute decision-maker for the person you care for. You can make a complaint if you don't get satisfactory answers or if you are disregarded. Sometimes, this arises because health care staff don't have a good understanding of the law.

'Sometimes you have to be assertive – I was told that my views as an attorney don't count – but when I pointed out the information from the Alzheimer Scotland website they changed their tune' Welfare Attorney, Scotland

Your right to a second medical opinion

In Scotland, if you and the doctor disagree about a health care decision, either of you can ask for a second opinion through the Mental Welfare Commission who will arrange for the person to be seen by an appropriate specialist. The specialist will also speak with you and the doctor. If the disagreement continues, it is possible to take the case to court and treatment can be halted.

In England, the law is different. You have a right to make a request for a second opinion but you don't have an automatic right to receive a second opinion.

Palliative care decisions

Wherever you live in the UK, when the time comes you should be involved in palliative care and end-of-life decisions. The person you care for should be given high quality palliative care and treated with dignity and respect.

You may be asked to sign a 'Do Not Resuscitate' (or similar) form. In deciding what to do it will be helpful for you, at this stressful time, to use the principles. Especially important in these circumstances is the principle relating to the person's past and present wishes and feelings, values and beliefs.

This will help you decide what will be in the best interests of the person, including considerations about quality of life as well as the medical consequences of the different options available.

For example: *A carer in the study reported feeling incompetent when asked to make a decision to allow 'PEG feeding' (through a tube to the stomach, because the person was no longer able to swallow). This is sometimes suggested as an alternative when the person is at risk of choking. However, it involves a very invasive and painful procedure and*

can lead to increased agitation and distress. Research findings indicate that PEG feeding is of little benefit for people with dementia towards the end of life because of the distress caused, and that the careful supervision of soft foods is likely to have the most benefit, particularly in relation to the pleasure of tasting food and participating in meal times. The carer was distressed and confused because she was not given full information about the risks and difficulties and did not receive any advice from a dietician. Her role as attorney with medical decision-making powers was recognised in this case but not followed through with objective information or expert advice about the consequences of the options for her mother. She was unable to make a 'best interests' decision and felt disempowered.

What if I don't have specific medical decision-making powers?

Even if you don't have specified powers for medical care and treatment decisions you have a right to be consulted by the doctor responsible for treating the person. In Scotland, you also have the same right to a second opinion as an attorney or guardian who does have those powers.

What decisions can the doctor make without me?

The doctor can go ahead and treat the person without involving you in the following circumstances:

- where the doctor assesses that the person is able to decide for themselves in relation to a specific treatment
- in an emergency - life or death situation
- where the person has been assessed as needing to be detained under the Mental Health (Care and Treatment) (Scotland) Act 2003 and placed on a Compulsory Treatment Order. In England, the same applies under the Mental Health Act. (But you can still make other decisions not covered by the mental health laws).

For further information about the rights of carers and consent to treatment, see the Resource list, page 61.

Consent to medical research

As a proxy decision-maker you have powers to consent to the person's participation in research and you need to be aware of the safeguards. You should feel free to ask questions about what is proposed. Even after the research has started, you have a right to stop the person's participation if the person or you are distressed by what is happening or if you are not happy with procedures.

The law allows research to be carried out if it will contribute significantly to scientific understanding of the disorder causing the person's lack of capacity, in this case dementia.

The research must not cause any discomfort or only minimal discomfort to the person and the person must not indicate any unwillingness to participate. The research must have been approved by the appropriate ethics committee.

13 Making financial decisions

As a financial attorney or guardian/deputy you will have received information from the Office of the Public Guardian (OPG) about the rules for looking after the person's money and property. This includes the need to keep the money of the person you are acting for separate and to keep a record of major items of spending. Guardians/deputies are required to produce management plans and to seek permissions to make certain types of decision, such as selling property.

You need to apply the principles set out in Part Two of this guide in reaching financial decisions and to think about the welfare implications for the person. Welfare and financial decision-making nearly always go together. If you have joint decision-making powers, you will need to consult and reach agreement with the other person.

The rules for financial attorneys, guardians and deputies are set out in more detail in the relevant guides and Code of Practice. See Resource list for further information.

Planning ahead and consultation

It is advisable to have a plan and to review it from time to time in anticipation of changes to the person's circumstances – whether the person is going to need to access more funds to meet costs of increasing care services; for transport, respite/holidays; clothing; household repairs; leisure activities which may require paid support for the person to continue.

As with welfare decisions, you should let others know of your plans and get their views. It is useful to meet with others with financial powers and those involved in the person's care to carry out a review and anticipate what might be needed, so that you can plan ahead.

Some family members may be unhappy that you are spending too much of the person's savings to improve their quality of life. Stick to the principles and let them know that the law requires you to do so. If anyone is unhappy with what you are doing, they can make a complaint to the Office of the Public Guardian.

15 Making decisions checklist – questions to ask yourself

Principle 1: Supporting the person to make their own decisions

- What can I do to help the person to make their own decision/s – how can I best explain information in a way they can understand; who else might be able to help?
- How can I introduce the subject of the person's future needs and find out what they would like to happen?
- How can I help the person communicate their decision to others?
- What action do I need to take to ensure the person's decision/s are respected and implemented?
- Do I need to make a plan or arrange a review?

Principle 2: Benefit/best interests

- What would the person chose to do for themselves to make their life better if they were able?
- Have I identified all possible options and do I have all the information I need about each?
- Will the decision/proposal (for example made by social services or health) provide the best outcome for the person in terms of meeting their emotional and social needs as well as their need for care and protection?
- Have I weighed up the options and is it clear which will provide maximum benefit for the person?

Principle 3: Which option/decision will be the least restrictive of the person's basic rights and freedom in order to achieve the benefit needed?

- What are the likely outcomes for the person from each option in terms of restricting the person's independence, including access to community, friends, activities they enjoy, etc?
- Is there another option which will maximise the benefit for the person even if it means restricting their freedom a bit more than other options?

Principle 4: Help the person to express their views and feelings

- How can I help the person to understand the choices to be made and assist them to express their views and feelings as far as possible?
- What do I know about what the person would want for themselves – taking into account their past way of life, values and beliefs, wishes and preferences?

Principle 5: Consult with others

- Who else do I need to contact (family/friends/other appointees, professionals, named person) about what I'm proposing so I can take account of their views?
- Can I anticipate a disagreement? What might I need to negotiate?
- Do I need specialist advice?

Principle 6: Encourage the person to use their skills and develop new ones

- What will help the person to use their abilities or slow their decline?

- What will help enhance their quality of life – what is important to them?
- Who can help me achieve this for the person?
- What other resources might be needed?

And finally

- Is the decision proportionate to the person's needs?
- Have I checked that I have the powers to decide or act on the matter in hand?
- Have I thought about what will happen if I decide to do nothing? (Doing nothing also has consequences – it may reduce choices later).

Remember: you are not alone and can seek help and support.

Part Three

16 Messages from carers in this study

About the carers who took part

Most of the carers who volunteered to participate in this study were family members aged between around 35 and 85. There were almost equal numbers of male and female carers who took part in either personal interviews or focus groups in Scotland and England. There was a great deal in common between their experiences, the challenges they met and the satisfaction they felt they got from their role as attorneys, guardians or deputies. There was also close agreement on the sort of assistance they would have liked.

The study also included interviews and focus groups with volunteer guardians and family members who were attorneys or guardians in The Netherlands and Germany. Whilst there are differences in the laws to protect people with impaired capacity, the principles for proxy decision-makers to follow are very similar. The Netherlands and Germany were chosen as countries to study because they have networks of support and training for volunteer guardians, which are also open to family members who are proxy decision-makers. Carers in these countries found both the peer and professional supports within these networks to be extremely helpful.

What all countries in the study had in common were too few dementia specialists in health and social care. This meant that diagnosis often came too late for the person to appoint an attorney and be involved in making their own decisions for as long as possible. An additional problem is that in a number of European countries, when a diagnosis is made, the information about it is withheld from the person. **This is a world-wide human rights challenge.**

Message to health care professionals

- Importance of knowing the diagnosis and its implications

Carers involved in this study said that the single most important factor which would have helped them at the point of diagnosis

would have been to have received more information about dementia and the implications, over time, for making decisions. This would have helped them to be prepared. Many found out too late and a guardianship application was most frequently made in response to a crisis.

An early explanation by healthcare professionals to both the person diagnosed and the carer would have allowed time for the person to consider appointing an attorney. This would have enabled important discussions to take place about future plans. Attorneys reported that, where this had happened, it made decision-making much easier at a later stage.

My mother was given an early diagnosis and this was explained to both of us by the consultant – it helped us to prepare. Mum appointed me as her attorney and this helped a lot with making decisions later. Attorney, Scotland

Find out all you can about the diagnosis as soon as possible and how it affects the person's mind– it came as a shock to me and too late to do things in a way which would have made it better for mum and easier for me. If only the doctor had explained it was more than just her memory going – if only I'd been told what to prepare for. Guardian, Scotland.

Message to other carers

Worried about taking on the responsibility? Messages from family member attorneys, guardians and deputies:

- Find out all you can, it's hard work, it takes time – but do it!
- Use your powers, negotiate what you want for the person
- Know your rights and the rights of the person
- Keep asking questions
- Don't feel guilty – you are doing your best
- Seek help – you are not alone!
- Give yourself a break – you need to survive.

- Find out all you can but 'Do it'

Do it – find out as much as you can about dementia and what is involved – know that it takes more time than you ever imagined – but you have the satisfaction that you are doing the best you can for the person you love. Attorney, Scotland

- Use your powers – negotiate what you want – keep asking questions

Keep asking questions – it's your right – the person can't ask for themselves so you need to be assertive. Don't give up.

Guardian, The Netherlands

Remember that you are not making the decision for yourself - you know the person well and what they would have wanted for themselves – you are acting as if you were them.

Guardian, Germany

It's hard when you have been through the courts to be appointed and then professionals don't recognise your authority – even social workers who should know - having to fight to be listened to. I have had to insist on being invited to care review meetings and, even so, they are often held at such short notice that I can't attend. Attorney, England

Social workers sometimes give you little choice and too little time to make a major decision. Don't be pushed into a decision you don't think is right for the person. Attorney, Scotland

- Don't feel guilty

Don't feel guilty whenever you make a decision that the person does not like – you have assessed the situation and had sleepless nights before acting as you think best for them. Deputy, England

- Seek help – you are not alone

I feel so alone in this role – isolated - I've never spoken to anyone about it – I've no close family and you don't want to burden friends. It would be good to have a peer group network to share experiences with. Guardian, Scotland

- Find a dementia expert who knows the capacity laws

The Consultant understood my powers and explained to the care home that they had to go to me for all decisions about her medication. Attorney, The Netherlands

- Find out about self-directed support

I needed to continue working when my husband was diagnosed with early onset dementia and had to give up his job. Social workers were great in getting me an individual budget to pay for 26 hours a week support. This meant he could be supported to do things he enjoyed – not be stuck in a day centre. Deputy, England

- Know your rights

The bank would not accept my power of attorney certificate at first – they said I had to bring my mother in with me with her driving licence, passport and utility bill – crazy - I said she had none of these as she was wheelchair bound and living in a care home and the reason I'm her attorney is because she has dementia. I insisted they ring their legal department or the Office of the Public Guardian to check the register. Eventually, they believed me. Carer, Scotland

- Give yourself a break – time out

Being a guardian is a tough job – you need to ensure you take care of yourself - allow yourself breaks or you reach exhaustion point and can't go on. Don't leave it too late to talk to social work about regular support so you can go out or have a holiday.

What proxy decision-makers said would help them

- **Information and support following diagnosis**

While none of the carers involved in the study said they regretted taking on the responsibility of being an attorney/guardian/deputy, they did feel that it would have helped if they had received more information and advice at an early stage from a range of agencies with duties under the law and others such as lawyers, financial bodies, etc. This points to the importance of early diagnosis and support following diagnosis.

- **Peer support and training**

The majority of carers in England and Scotland said they would welcome a peer support network for guardians and attorneys and the opportunity to attend a series of training sessions on the law and decision-making, including sessions on thinking through ethical issues.

16 Action to support lay proxies

Statistics show that increasing numbers of us are registering powers of attorney. On the other side of the equation, more of us are being appointed as attorneys by older relatives and friends. Statistics held by the Office of the Public Guardian in Scotland show that more than 60% of welfare guardians are family members caring for someone with dementia. One in four of us living to over 80 is likely to develop dementia and may need a proxy decision-maker. It is therefore in the interests of the human rights of us all that the information, support and education needs of proxy decision-makers are formally recognised and met.

A summary report with recommendations to policy makers and professionals has been published to accompany this guide and will be used to influence improvements in meeting the needs of lay proxies in fulfilling their duty to the person they are acting for.

Alzheimer Scotland will continue to work in a variety of ways to promote the human rights of people with dementia and those appointed to make decisions and act on their behalf. We will also continue to work with stakeholder groups supporting the rights of other adults who lack capacity and their carers.

Further information

Where to get help

Scotland - organisations

Office of the Public Guardian

Tel: 01324 678 300

Website: www.publicguardian-scotland.gov.uk

Registers all powers of attorney and guardianships; provides information and advice to financial guardians and financial/continuing attorneys; can investigate concerns where property or financial affairs of an adult with incapacity seem to be at risk.

Mental Welfare Commission Scotland

Tel: 0131 313 8777 or

User and carer advice line: 0800 389 6809

Website: www.mwscot.org.uk www.mwscot.org.uk

An independent organisation working to safeguard the rights and welfare of everyone with a mental illness, dementia or other mental disorder; provides advice and information about rights and best practice in relation to the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003.

Alzheimer Scotland

Tel: 0131 243 1453

Helpline: 0808 808 3000

Website: www.alzscot.org

Scotland's leading dementia charity, providing: 24hr Freephone Dementia Helpline; guides to dementia care; specialist dementia services in the community; campaigns for the rights of people with dementia and their carers.

Citizen's Advice Bureau

Tel: 0131 550 1000

Website: www.cas.org.uk

The Scottish Independent Advocacy Alliance

The website has a map giving details of local independent advocacy services in all parts of Scotland.

www.siaa.org.uk

Tel. 0131 260 5380

Social Work Department, Local Authorities

Local authorities have a duty to supervise welfare guardians and to provide advice and information on request to welfare guardians and welfare attorneys. They can investigate complaints if misuse of powers by welfare guardians or attorneys is suspected and apply to the sheriff court to take action, e.g. to reduce/remove powers; supervise a welfare attorney.

Contact details will be in the phone book under local authority.

England and Wales – organisations

Office of the Public Guardian

Tel: 0300 456 0300

Website: www.justice.gov.uk/about/opg

Registers attorneys and deputies; provides information and advice.

Alzheimer's Society

Tel: 020 7423 3500

Helpline: 0845 300 0336 opening hours 8.30 - 6.30 (Mon - Fri)

Website: www.alzheimers.org.uk

Leading dementia charity in England, Wales and N.Ireland, providing information, specialist dementia services and campaigns for the rights of people with dementia and their carers.

Citizens Advice Bureau

Tel: 08444 111 444 (England) 08444 77 2020 (Wales)

Website: www.citizensadvice.org.uk

Social Services Department

Contact details will be in the phone book under local authority.

Resource list

Scotland

Scottish Government: Adults with Incapacity (Scotland) Act 2000 Codes of Practice available for download at: Adults with Incapacity (Scotland) Act 2000 www.scotland.gov.uk/Topics/Justice/law/awi ; or telephone 0131 244 3581.

- Guardians: Code of Practice for persons authorised under intervention orders and guardians.
- Attorneys: Code of Practice for Continuing and Welfare Attorneys.
- Local Authorities: Code of Practice for local authorities exercising functions under the 2000 Act.
- Code of Practice (Third edition) for practitioners authorised to carry out medical treatment or research under Part 5 of the Act.
- Making Decisions – Your Rights. For People with Dementia and Carers. DVD (also available from Alzheimer Scotland).
- It's your decision. The Adults with Incapacity (Scotland) Act can help you when you are unable to decide things for yourself [easy read guide].
- Communication and assessing capacity: a guide for social work and health care staff. Scottish Government. This practical guide is useful for anyone in the UK involved in assessing capacity or decision-making for an adult with a mental disorder including dementia.
www.scotland.gov.uk/Publications/2008/02/01151101/0.
- Guardianship and Intervention Orders - making an application. A Guide for carers. Scottish Government (2007).
- A Guide to making a Power of Attorney. Office of the Public Guardian (Scotland). Available from www.publicguardian-scotland.gov.uk

Mental Welfare Commission Scotland

Available at www.mwscot.org.uk

Service user and carer leaflets

- Welfare Guardianship: making sure decisions are in a person's best interests.
- Money matters – a quick guide to managing the finances of an adult with incapacity.

Good practice guides:

- Covert medication – legal and practical guidance
Covert medication is the administration of any medical treatment in a disguised form.
- Right to Treat? Delivering physical healthcare to people who lack capacity and refuse or resist treatment.
- Safe to wander? Principles and guidance on good practice when considering the use of wandering technologies for people with dementia and related disorders.
- Rights, risks and limits to freedom: principles and good practice guidance for practitioners considering restraint in residential care settings.
- Consenting Adults? Guidance for professionals and carers when considering rights and risks in sexual relationships involving people with mental disorder.
- Working with the Adults with Incapacity (Scotland) Act 2000. Information and guidance for people working in adult care settings.
- Carers and confidentiality: developing effective relationships between practitioners and carers.
- Supervising and supporting welfare guardians: practice guide

Investigation Report

- Best of Intentions. Report from our investigation into the care and treatment of Mrs I (July 2010).

Other guides for Scotland

Available from www.alzscot.org or the Dementia Helpline on 0808 808 3000

Standards of care for dementia in Scotland. A guide for people with dementia and their carers. Alzheimer Scotland. April 2012.

Taking Charge: a short guide to self-directed support for people with dementia and their carers.

Caring and consent: your right to be involved in decisions about the health care of the adult you care for. Consumer Focus Scotland. Available at www.hris.org.uk

England and Wales

Department of Health: Mental Capacity Act 2005 Codes and publications

- Mental Capacity Act 2005 Code of Practice.
www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act
- Making decisions: a guide for family, friends and other unpaid carers. Office of the Public Guardian. www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act
- Mental Capacity Act 2005. Deprivation of liberty safeguards: a guide for family, friends and unpaid carers.
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_095895
- Mental Health Act 2007 Code of Practice.
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084597

See also:

- Dementia Choices – information and guidance on self-directed support for people with dementia, their families and friends. www.mentalhealth.org.uk/our-work/research/research-projects/dementia-choices
- The Mental Capacity Act 2005: Decision-making and advance planning. Alzheimer’s Society
- Advance Decision: Explanatory information and form. Alzheimer’s Society. Factsheet 463
- Making Difficult Decisions (forthcoming). Alzheimer’s Society.

Other resources/useful references

- Charter of Rights for people with dementia and their carers www.dementiarights.org/charter-of-rights/ or printed copy available from Alzheimer Scotland (see above)
- UN Convention on the Rights of Persons with Disabilities www.un.org/disabilities/convention/conventionfull.shtml
- Dementia: ethical issues – a guide to the report. Nuffield Council on Bioethics. Available to download at: www.nuffieldbioethics.org/dementia or e-mail: bioethics@nuffieldbioethics.org

Glossary

Words and terms used in this guide

Proxy decision-maker: this term is used to describe those legally appointed to make decisions or act on behalf of someone who is unable to do so for themselves in Scotland, England or Wales. However the legal terms used differ slightly:

Scotland: in Scotland the person appointed as proxy for someone with dementia living in Scotland will be a welfare and/or continuing (financial) attorney; or a welfare and/or financial guardian

England, Wales: in England and Wales the person appointed for someone with dementia living in England or Wales will be a Financial or welfare attorney authorised under a Lasting Power of Attorney; or court appointed-deputy.

Principles: the laws in Scotland, England and Wales contain the principles or rules which must be followed by all proxy decision-makers. Whilst there are some differences between these in the Acts, the values on which they are based are the same. Proxy decision-makers in the UK must apply the same sorts of considerations in reaching decisions. However there are some differences in processes and procedures so it is important that proxy decision-makers also refer to the appropriate code of practice. This guide sometimes refers to the principles as 'rules'.

Benefit and best interests: The Adults with Incapacity (Scotland) Act states that any action or decision made for a person who lacks capacity must be, primarily, for the person's 'benefit'.

The Mental Capacity Act uses the term 'best interests' – any decision made for the person must be in their best interests.

In this guide the terms are used interchangeably because the intention in both Acts is the same: any decision you take as proxy decision-maker must be justified by the benefit it provides for the person - it must be in their best interests. If challenged, you need

to be able to show how you have used the principles to reach the decision you have made.

Person: this is the word used sometimes to refer to ‘the person with dementia’; and ‘**their**’ is used instead of ‘his or her’. This is to make the guide more user friendly.

Carer: this term is used to refer to a family member, partner, friend (unpaid carer/s) involved with the care and support of the person with dementia.

Deprivation of liberty: article 5 of the European Convention on Human Rights provides that everyone has a right to liberty and security of person. While there is no definition, deprivation of liberty will depend on the circumstances of each individual case. For example, restrictions on freedom, such as living in a care home with a locked door, does not automatically mean the person is deprived of liberty so long as there is good access to family, community etc. For England and Wales see: Deprivation of Liberty Safeguards Mental Capacity Act; for Scotland see Code of Practice for Local Authorities Exercising Functions under the 2000 Act, Annex A ‘assessing whether the proposed care intervention amounts to deprivation of liberty in terms of Article 5, ECHR.’

Palliative care: an approach which aims to improve quality of life for people and their families facing problems associated life threatening illnesses through relief of suffering.

Psychoactive medication: prescribed medicine which affects brain function such as antipsychotic drugs or anti-depressants.

Dementia: making decisions

Alzheimer Scotland is committed to improving the lives and opportunities of people with dementia, their families, partners and others providing support and care. We do this by campaigning for the rights of people with dementia and their families, partners and friends. We provide specialist dementia care services across Scotland and raise funds to provide our 24hr Freephone Dementia Helpline (0808 808 3000), our network of Dementia Advisors; our dementia nurse specialists and our Dementia Research Centre.

This practical guide aims to help family members, partners and friends who have been appointed under the following laws to act as proxy decision-makers for someone with dementia in Scotland, England and Wales.

- Scotland: Adults with Incapacity (Scotland) Act 2000
- England and Wales: Mental Capacity Act 2005

Whilst there are some important differences between these laws across the UK and how they are implemented, the principles are based on the same set of values and principles set out in the Human Rights Act 1998.

The rights of people with dementia are not always well understood and their proxy decision-makers often face challenges. This guide aims to support attorneys, guardians and deputies in overcoming some of the barriers they may face. It will also be helpful to others in the UK and elsewhere in the world involved with the care of people with dementia.

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www.alzscot.org Helpline 0808 808 3000