



Decide for yourself!

**A guide to making decisions
for people with memory problems or dementia and their families**

Geraldine Boyle and Katherine Ludwin

May 2012

Contents	Page Number
Introduction	3
The Mental Capacity Act	3
Tips for making decisions	4
Getting help and accepting help	5
Tips for helping someone else to make decisions	6
The decisions we make every day	7
Making difficult decisions	19
Other resources and related organisations	25
Acknowledgements	30

Introduction

This guide focuses on everyday life and the sorts of routine decisions we make on a daily basis - such as what shopping is needed and what bills to pay. We *all* find it difficult to make decisions at times, as it is not always clear what to do. If you have memory problems or dementia, you may also find it difficult to make decisions at times. Getting a bit of advice from those ‘in the know’ makes it easier for *all of us* to make decisions. So, the aim of this guide is to tell you how other families manage and to pass on their experiences. The guide is based on research we carried out with couples living with dementia – they told us their stories and gave suggestions for making life easier.

We hope you find this guide helpful.

The Mental Capacity Act

The Mental Capacity Act is an important law that protects the rights of people who may find making decisions difficult. This law gives people with dementia the right to make decisions *where they are still able*. If you are a family member of someone with memory problems, it’s important to give your relative the opportunity to make the decisions they can still make. Being included in this way can make a big difference to your loved one’s well-being. In addition, the guidance you give to your relative can make a difference to how they manage to decide for themselves.

Tips for making decisions

- ❖ Take your time!
- ❖ Ask your family to explain things to you.
- ❖ Avoid making decisions when you're feeling stressed – wait until you're feeling happy and calm.
- ❖ Take decisions a step at a time.
- ❖ Focusing on a limited number of choices makes decisions easier.
- ❖ Avoid planning too far in advance.
- ❖ Use a diary or a calendar to remind you of appointments or family events.
- ❖ Ask for help if you need it.
- ❖ Feel good about yourself – you're a star!

Getting help and accepting help

Even though making decisions can sometimes be a bit of a challenge, it helps to acknowledge this and to ask your family and friends to help you. It can also help to get advice from other people living with memory problems – you can meet up with them at wellbeing cafes or support groups (for example, run by the Alzheimer's Society). Let people know if you also need practical help - we all need help at times. Of course, help is a two-way thing, so give yourself a pat on the back when you help someone else out - for example, with jobs around the house or visiting a sick friend.

If you're a relative of someone with memory problems, it's important that they are given the opportunity to do things they still enjoy (such as cooking or shopping). However, they may need a bit of guidance or help from you with doing these tasks. Try and avoid doing things that your relative is able to do for themselves. On the other hand, if they're still doing tasks that you could do instead (such as housework), try and help out! It may be that they could use this time to do other things they enjoy (such as hobbies) which would help to promote their well-being.

Tips for helping someone else to make decisions

Preparing for decisions

- ❖ Ensure you give your relative the chance to make a decision (don't assume they can't do this until they've tried).
- ❖ Avoid planning too far in advance - use the start of the day to discuss what will happen the rest of the day.
- ❖ Using written text, pictures or photos can make things clearer.
- ❖ Avoid raising issues if you're feeling tired or stressed – choose a time when you're feeling calm.
- ❖ Think before you speak!
- ❖ A bit of humour can lighten any decision.

Making decisions

- ❖ Give your relative time to prepare (for example, explain if you're expecting visitors).
- ❖ Allow them time to think things through.
- ❖ Explain things more simply (e.g. reword in a different way).
- ❖ If they're having difficulty deciding, put the decision off until they can think more clearly.
- ❖ Listen to what they're saying.
- ❖ Imagine how your relative is feeling.
- ❖ Pay attention to their body language (if their speech is affected).
- ❖ Be patient with your relative and accept how they are now.
- ❖ Be patient with yourself.

The decisions we make every day

Deciding what to wear

Decide for yourself!



Choose what you want to wear.



It's easier if you focus on two choices only.



Take your time with dressing – don't hurry.

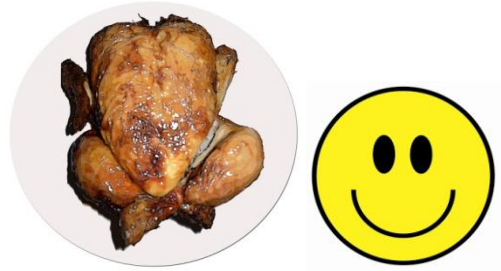
Helping someone else to decide

- Give your relative the chance to choose their clothes.
- Limit the number of choices (two options is best).
- Show them the choices available (for example, different shirts).
- Try and avoid taking over - prompt them instead.
- Buy clothes that are easy to fasten.
- Tell them when they have done well.

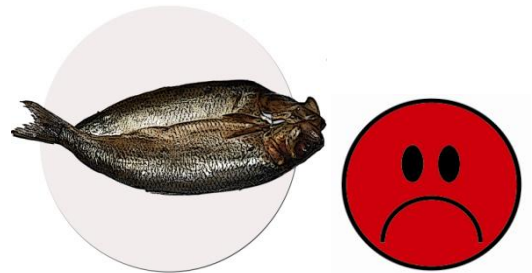
Deciding what to eat

Decide for yourself!

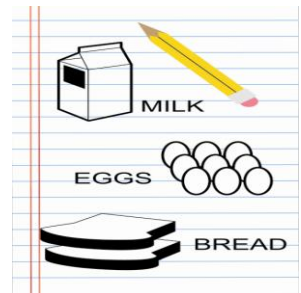
Think about the foods you enjoy.



Tell your family what you don't like to eat now.



Write a shopping list to remind you what to buy at the supermarket.



A little of what you fancy does you good!



Helping someone else to decide

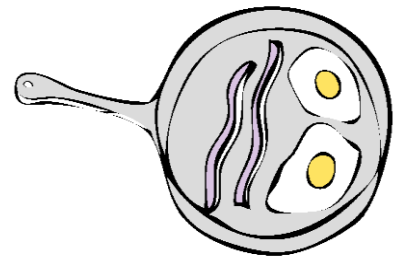
- Limit the number of food choices.
- Show the food choices available (for example, fish or curry).
- Show pictures of food (say, from a recipe book).
- Notice when your relative expresses a choice in some other way (for example, smiling or picking up a particular food).
- If they have difficulty expressing a choice, take account of their favourite foods.

Deciding who's going to cook

Decide for yourself!



Use a cookery book if a recipe is hard to remember.



If some dishes are too hard to cook now, cook simple dishes.



Use a cooker timer to remind you when the food is cooked.



If you need a bit of help, ask your family.

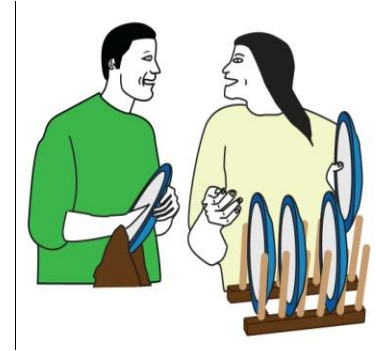
Helping someone else to decide

- Give your relative the chance to cook if they still want to.
- Avoid taking over this task - try and help them out instead.
- You can help them find things (such as saucepans and ingredients).
- Families help each other out – cook it together!

Deciding what housework needs to be done

Decide for yourself!

Housework is hard work - ask your family to help out.



Be proud of yourself for what you can manage.



Tell your family if you can't manage housework now.

Helping someone else to decide

- You may need to help out with organising housework (for example, planning a trip to the supermarket).
- Your relative might need prompting at times (for example, with setting the washing machine).
- Check that your relative isn't doing too much now.
- Share the housework!

Deciding what to do for the day

Decide for yourself!

Spend time doing your favourite things (such as dancing).



If you find it hard to keep up a hobby, try a new hobby.



Keep in touch with friends and family.



It's good to make new friends.



Helping someone else to decide

- Give your relative the chance to decide how they want to spend their time.
- If they're finding it hard to make up their mind, suggest a couple of options.
- It's nice to do things together; at other times, it's good to have separate interests.
- Ask a friend to keep your relative company if you are going to be out for a long period (or check if there is a befriending or other support service available).
- Tell your family and friends when you need their support.

Deciding what to buy or what bills to pay

Decide for yourself!



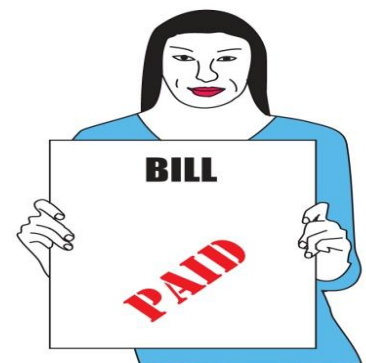
If you are not sure what to pay for things, ask your family.



You could get your bills paid automatically (from a bank account).



Staff in the bank or post office can help (tell them you have memory problems).



Give yourself a pat on the back when you pay bills.

Helping someone else to decide

- Give your relative the chance to continue paying in shops.
- Give them help when they need it (for example, with counting money).
- Acknowledge your relative's skills (say, if they still pay bills).
- Where possible, give your relative the chance to have a say in big financial decisions (such as selling your house).
- If you think you'll need to take over managing the bills at some stage, get ready now so you know what's needed.
- If you need advice about managing money, ask your family or talk to a financial advisor (contact details for advice organisations are provided later).

Making difficult decisions

Although this guide focuses on the sorts of decisions we make every day, it's often possible for people with dementia to be involved in making more difficult decisions.

These types of decisions include whether your relative should continue driving or go to a day centre or whether to apply for a Lasting Power of Attorney. Difficult decisions can be easier for someone to make if the issue is made simpler and they're given time to think about the decision and guidance on the options available. It's important to give your relative a say in any big decisions, even if the topic is quite emotive. Bear in mind that the Mental Capacity Act gives people with dementia the right to make decisions where they are still able to do so. Involving people with dementia in decisions (whether big or small) gives them a sense of purpose and promotes their well-being.

Deciding whether to continue driving

Decide for yourself!



If it is difficult to remember directions, ask your family to guide you.

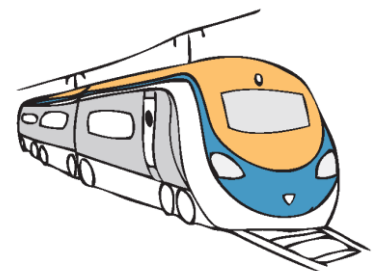


Ask a family member to accompany you when driving.

If driving is hard now, ask your family to take over.



You should tell the DVLA (Driver and Vehicle Licensing Agency) if you have dementia.



Using a bus or train saves money!

Helping someone else to decide

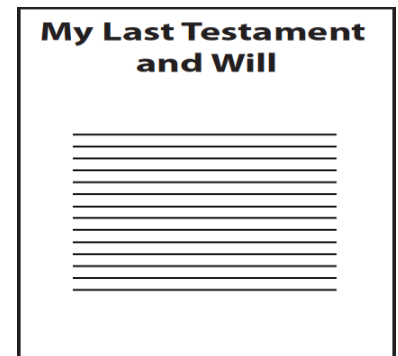
- Prompt your relative if they forget a route.
- If your relative is finding it hard to drive but doesn't want to give up, get advice from your family or a health professional.
- Give your relative a chance to have a say in any decision to stop driving.

Planning for the future

Decide for yourself!

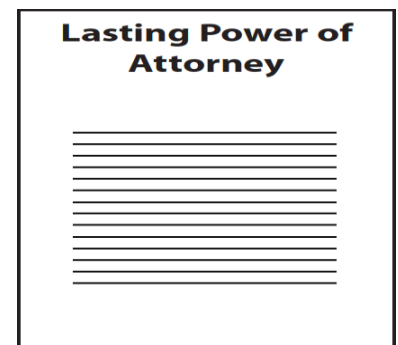
We all want to plan for our future.

Make a will so your money and property is divided as you wish when you die.



You may want a relative to make decisions for you if it becomes too hard to make these yourself (for example, about your money or any care needed).

This is called a Lasting Power of Attorney.



Choosing someone you trust to make decisions for you can give you peace of mind.



Helping someone else to decide

- Ask your relative if they want to designate a Lasting Power of Attorney.
- The Lasting Power of Attorney can apply to decisions about their personal welfare or their property and financial affairs (or both).
- Ensure you register the Lasting Power of Attorney with the Office of the Public Guardian (see below for contact details).
- If you make a decision on your relative's behalf using a Lasting Power of Attorney, you must decide in their best interests.

Making decisions in advance

Decide for yourself!

You can make a decision in advance just in case you cannot make this decision later on (for example, relating to care preferences).



If you make an advance decision, tell your family your wishes.



It's a good idea to write your wishes down.

You can make clear if you do not want certain medical treatment if you become very ill (such as life-sustaining treatment).



You could get advice about this (say, from a nurse).

Other resources and related organisations

If you need further information or advice on making particular decisions, refer to the following resources and organisations:

Making decisions...about your health, welfare or finances. Who decides when you can't?

This is a short guide about the Mental Capacity Act for people who may be unable to make some decisions for themselves. It explains how the law protects your rights and how to get support if you need help with making decisions or cannot make these decisions by yourself.

The guide was produced by the Ministry of Justice, the Office of the Public Guardian, and the Department of Health. It can be obtained from the following website:

www.justice.gov.uk/downloads/guidance/protecting-the-vulnerable/mca/opg-601-0409.pdf

Making decisions: A guide for family, friends and other unpaid carers

This is a short guide which explains how you can help a family member or friend who is unable to make some decisions for themselves. It can be obtained from the following website:

<http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf>

The Alzheimer's Society

The Alzheimer's Society is a leading support and research charity for people with dementia, their families and carers. The Society provides up-to-date information to help with every aspect of living with dementia.

Their contact details are:

Alzheimer's Society
Devon House
58 St Katharine's Way
London E1W 1LB

The phone number for their helpline is: (0845) 3000336

Alternatively, you can email them at: enquiries@alzheimers.org.uk

Their website address is: www.alzheimers.org.uk

The Alzheimer's Society also has local offices in England and Wales where you can get information and advice and find out about the support available in your area (including services for people from Black and Minority Ethnic communities). There is also information available on their website and via their phone line on Lesbian, Gay, Bisexual, and Transgender support. You can find contact details for your local branch by looking in the telephone directory or ringing the Society's helpline.

Carers Trust

The Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

Their contact details are:

Carers Trust
32-36 Loman Street
London SE1 0EH

Their telephone number is: (0844) 800 4361

Their email address is info@carers.org
Their website address is www.carers.org

The Trust has a network of local carers' centres and schemes to ensure that information, advice and practical support are available to all carers across the UK. The website contains useful information about being a carer. You can find details of your local services by searching the website or ringing the above number.

Citizens Advice Bureau

The Citizens Advice Bureau is a free, independent, confidential advice service which can help people resolve legal, money, and other problems. They have local branches where you can get information and advice in person. You can find out about your nearest local branch by ringing the telephone advice service, or checking out their website.

Their contact details are:

Citizens Advice Bureau
Myddelton House
115-123 Pentonville Road
London N1 9LZ

To get advice by phone (in England), ring: (08444) 111444

Their main website address is: www.citizensadvice.org.uk
Their self-help website address is: www.adviceguide.org.uk

Age UK

Age UK aim to improve later life for everyone. They provide advice and advocacy to older people on a wide range of issues. There are also Age UK services and groups in many local areas.

Their contact details are:

Tavis House
1-6 Tavistock Square
London WC1H 9NA

To get advice by phone, ring: (0800) 1696565

Their website address is: www.ageuk.org.uk

Office of the Public Guardian

The Office of the Public Guardian protects people who are unable to make decisions for themselves. They can provide a range of information, including advice on how to obtain a Lasting Power of Attorney.

Their contact details are:

Office of the Public Guardian
PO Box 16185
Birmingham
B2 2WH

Their telephone number is: (0300) 456 0300

You can email them at: customerservices@publicguardian.gsi.gov.uk

Their website address is: www.justice.gov.uk/about/opg.htm

Adult Social Care

The Adult Social Care Department in your local council can provide advice on local services and support available to people with dementia and their carers. You can find their contact details in the local phone directory or via the internet.

Care Quality Commission

The Care Quality Commission is a national organisation that checks whether hospitals, care homes and care services are meeting government standards. They can be contacted for information or advice when you have a serious concern about a person's safety or wellbeing and the kind of care they are receiving, or to report a concern regarding a care service.

Their contact details are:

Care Quality Commission
National Customer Service Centre
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

To contact their National Customer Service Centre, phone: (03000) 616161

Their website address is: www.cqc.org.uk/

Equality and Human Rights Commission

The Equality and Human Rights Commission is a national organisation set up to tackle discrimination in relation to six areas, including age and disability. They provide information and advice relating to age discrimination.

To obtain advice about discrimination, phone: (0845) 6046610 (England) or (0845) 6048810 (Wales).

Their website address is: www.equalityhumanrights.com/

Acknowledgements



The research on which this guide was based was funded by a grant from the Economic and Social Research Council (awarded to Geraldine Boyle from the University of Bradford and Lorna Warren from the University of Sheffield). Katherine Ludwin and Elaine Argyle were the project Research Assistants. The pictures were designed by Samuel Wyatt and Kelsey Emblow, Graphic Design course students from Bradford College.

We would like to thank all the couples who took part in our research.

Please let us know if you found this guide helpful:

Give your comments (by phone or email) to Geraldine Boyle at the Centre for Applied Social Research, University of Bradford:

Phone: (01274) 236602

Email: g.m.boyle@bradford.ac.uk

Website: www.applied-social-research.brad.ac.uk/