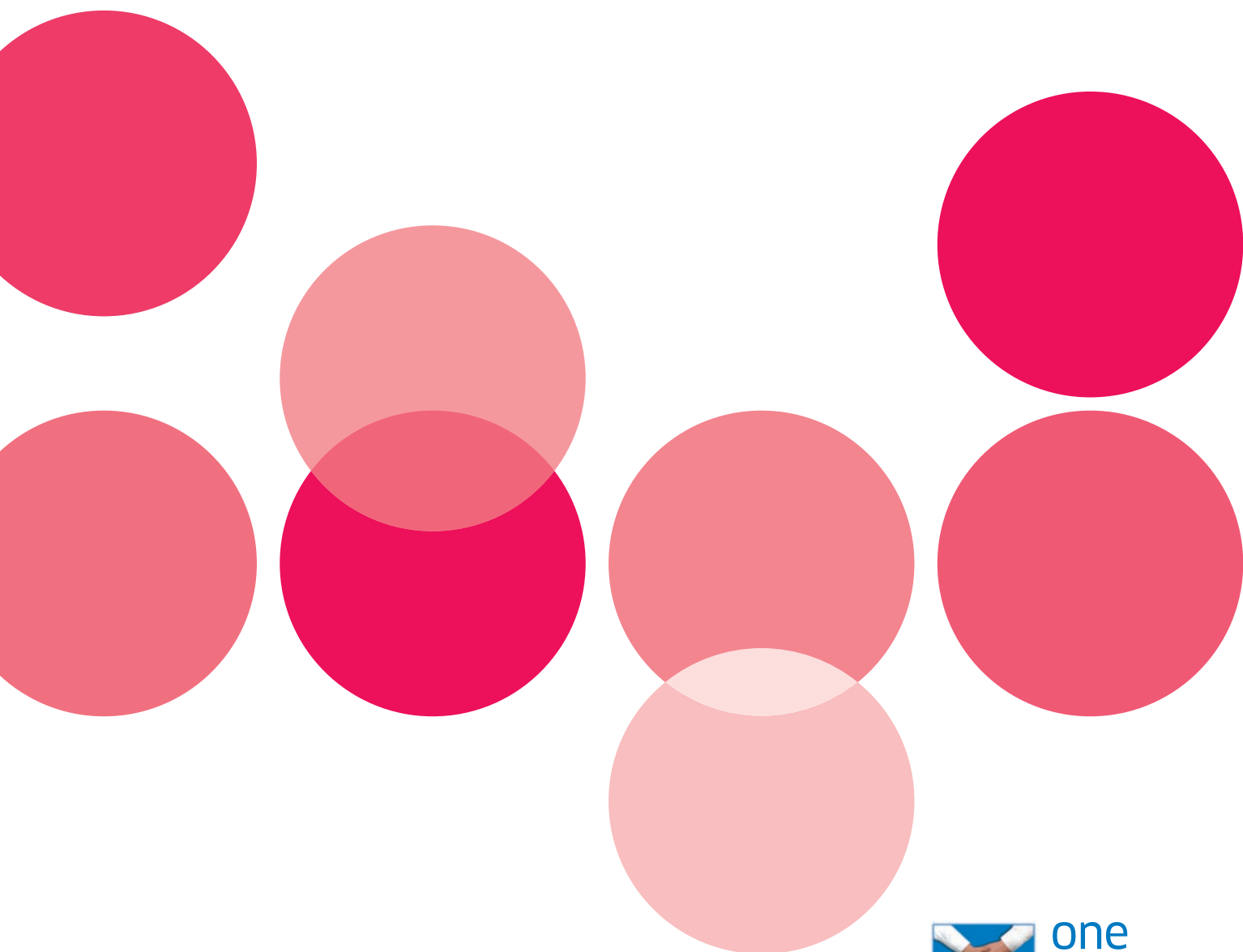


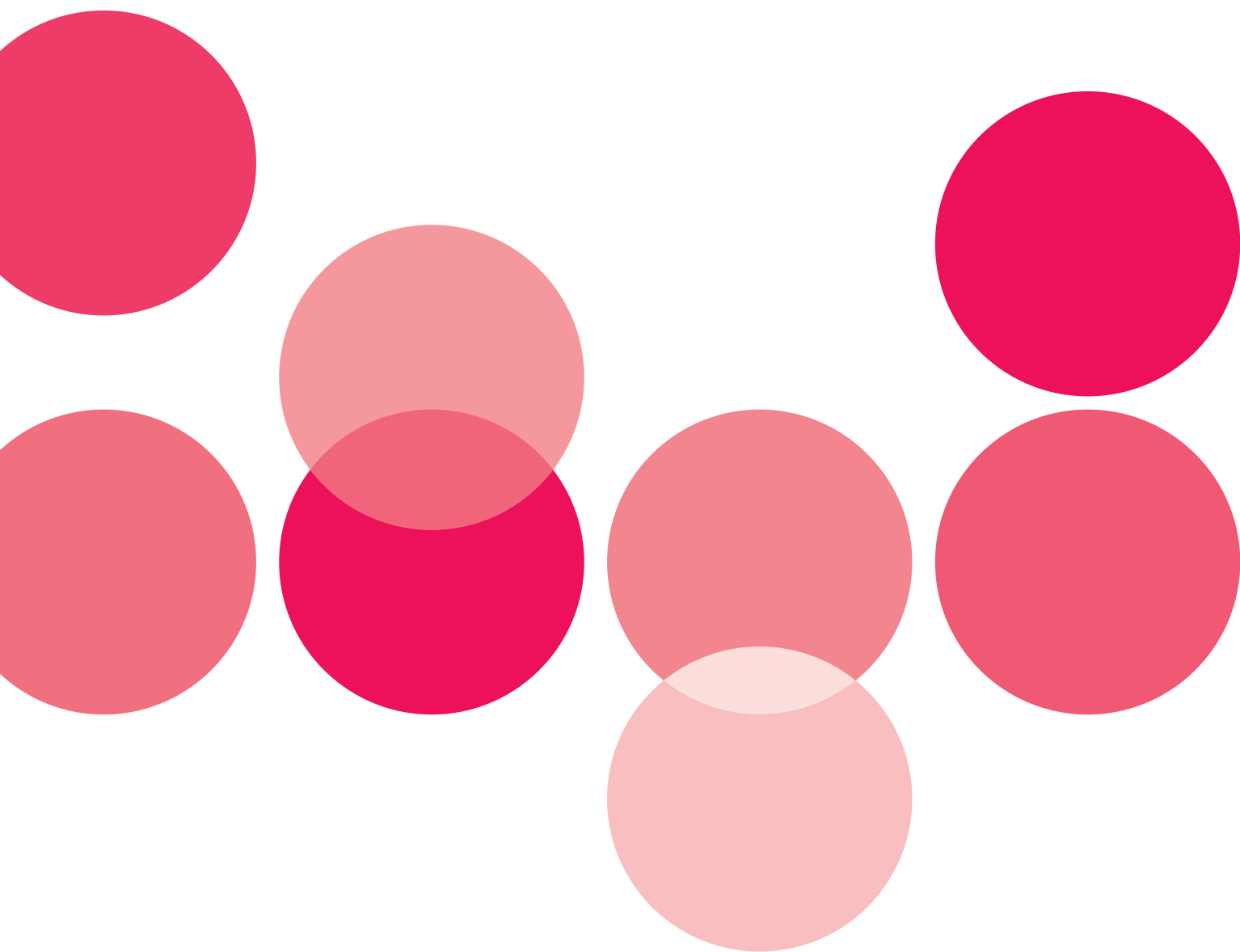
Communication and Assessing Capacity

A guide for social work and health care staff



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Adults with Incapacity (Scotland) Act 2000
Communication and Assessing Capacity
A guide for social work and health care staff

Acknowledgement

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Civil and International Justice Directorate
The Scottish Government

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Contents

1	Introduction	1
	• Who is this guide for?	2
	• Background	2
	• The presumption of capacity	3
	• Impaired capacity	4
2	Supporting decision-making	8
3	Assessing Capacity Interview: money and property matters	12
	• Steps to take	
	- Step 1: Explore the factual understanding of present financial circumstances. Points to consider	12
	- Step 2: Identify areas of unmet financial need. Points to consider	14
	- Step 3: Explore decision-making within critical areas of unmet need Points to consider	15
4	Assessing Capacity Interview: personal care	16
	• Steps to take	
	- Step 1: Explore factual understanding of present personal care circumstances. Points to consider	16
	- Step 2: Identify areas of unmet need in each personal care domain being investigated. Points to consider	17
	- Step 3: Explore decision-making within critical areas of unmet need. Points to consider	17
5	Performing capacity assessment with specific care groups	19
	• People with neurological conditions	20
	• People with dementia	22
	• People with a learning disability	24
	• People with severe or chronic mental illness	26
	• People with alcohol related brain injury	27
	• People affected by a severe stroke	29
	Appendix 1: Sample interview questions – money and property	30
	Appendix 2: Sample interview questions – personal care	32
	Appendix 3: Useful resources	34
	Appendix 4: Adults with Incapacity (Scotland) Act – provisions and principles	38



Chapter 1



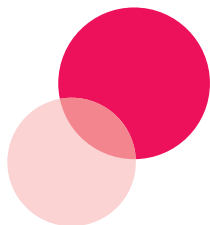
INTRODUCTION

Why has this guide been produced?

- 1 This guide has been produced to support professionals in assessing the capacity of individuals who may come under protection of the Adults with Incapacity (Scotland) Act 2000. The need for a practical guide was identified by an advisory group of lead officers from within local authorities which was set up to review the Code of Practice for Local Authorities Exercising Functions under the Act¹. The group felt that practitioners involved in conducting community care assessments would be helped by having more detailed guidance on communication and assessment of capacity than the code provides. The guide also reflects the need for a greater recognition that the quality of communication and the appropriateness of methods used to enable understanding, underpin the assessment of a person's capacity to make decisions. A working draft was circulated for comment to a wide range of interests and received an extremely positive response. However, it is not to be regarded as the 'definitive' guide – we are all on a 'learning curve' in this area – nationally and in the wider world – and for this reason it is available only on the website and will be subject to change as our experience and knowledge grows.

The Scottish Government is committed to ensuring that the human rights of people with impaired decision-making capacity are upheld and it is hoped that this guide will help practitioners in their efforts to achieve this important aim.

¹ Scottish Executive Social Research (2004) The Adults with Incapacity (Scotland) Act 2000 Learning from Experience.



Who is this guide for?

- 2 This guide is primarily for social work and health care staff in Scotland, including:
- care managers and other health and social care staff involved in carrying out community care assessments where the person appears to have difficulties in making decisions or acting in their own interests due to a mental disorder or a severe communication difficulty caused by a physical condition;
 - health and social care staff, including clinical psychologists, involved in the capacity assessment process where a formal intervention under the Adults with Incapacity Act is being applied for;
 - medical practitioners involved in both the early stage of a multi-disciplinary assessment process and/or where a formal assessment of capacity is needed because an intervention under the Act is being proposed. Doctors have principal responsibility for the formal assessment of capacity – in relation money management under Part 3 (Access to Funds) and financial and/or personal welfare decision-making under Part 6 (intervention orders and guardianship). However the importance of multi-disciplinary assessment is stressed here and in the codes of practice.

This guide does not cover the assessment of capacity in relation to medical treatment decisions or consent to medical research (see the 2000 Act Part 5 Code of Practice). However some references on this topic are included in Appendix 3.

For further information about the 2000 Act visit the Scottish Government's website: www.scotland.gov.uk/justice/incapacity.

Background

- 3 Capacity is the ability to understand information relevant to a decision or action and to appreciate the reasonably foreseeable consequences of taking or not taking that action or decision. 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 for themselves and to support their families and carers in managing and safeguarding the individual's welfare and finances.

The Act covers people whose incapacity is caused by a mental disorder such as dementia, learning disability, acquired brain injury, severe mental illness or personality disorder. It also covers people who are unable to communicate due to a physical condition such as a severe stroke or sensory impairment. A diagnosis of any of these conditions does not mean that the decision-making capacity of the person is impaired. There are, for example, many people with dementia or learning disabilities who are capable of making all or nearly all decisions for themselves. However, if someone with a mental disorder appears to be struggling to make or act on financial, welfare or healthcare decisions, the possibility of some incapacity should at least be considered.

The need for help and support does not automatically mean that the person cannot make the decision or decisions in hand. In accordance with the key mandatory principle of the Act, every effort must be made to support the person in communicating his/her views and feelings. No one else can act or make decisions for someone who is capable of doing so for his/herself.

The presumption of capacity

- 4 The starting point for assessing someone's capacity to make a particular decision is always the assumption that the individual has capacity. In legal proceedings the burden of proof will fall on the person who asserts that capacity is lacking. A court must be satisfied that on the balance of probabilities, capacity has been shown to be lacking.

'There is no all-purpose test for incapacity. The test depends on the decision to be taken... or task to be done. The principles of least restrictive alternatives and maximising the person's capacity underline the importance of not making blanket assessments of incapacity and recognising any residual capacity an adult has'.
Hilary Patrick²

The 2000 Act was designed to promote personal autonomy, as well as protect adults who lack capacity to make some or all decisions for themselves. These values are fundamental to our society and therefore for all citizens unless they need protection. **This guideline emphasises the crucial relationship between the ability of the professional to find appropriate ways of communicating with the person and the assessment of capacity to make the decision in hand.** The challenge is to find ways to help the person to understand what decision or decisions need to be made and why – and to support him/her to reach his/her own decision as far as possible. When an assessment of capacity is undertaken, the fundamental issue under consideration is the person's ability to decide.

² Patrick, Hilary et al Mental Health, Incapacity and the Law in Scotland, Tottel Publishing, 2006

A person is not to be treated as unable to make a decision merely because he/she makes an eccentric/unusual or unwise decision.

- 5 Presented with similar circumstances many of us will make different decisions because we give greater weight to some factors rather than others. Factors influencing our decisions will be our own values, preferences and previous experiences. Some people are keener to express their own individuality or more willing to take risks than others.

However, there may be cause for concern if an individual repeatedly makes unwise decisions and place him/her at significant risk of harm or serious exploitation. Concern may be triggered if a person makes a particular decision which defies all notions of rationality and/or is markedly out of character. In these situations it would be relevant to look at the person's past decisions and choices. While such situations should not automatically lead to the conclusion that capacity is lacking, they might raise doubts about capacity and indicate the need for further investigation.

Impaired capacity

- 6 In order to decide whether an individual has capacity to make a particular decision you need to consider:
- does the person have a mental disorder (which includes mental illness, learning disability, dementia and acquired brain injury), or severe communication difficulty because of a physical disability (such as stroke or severe sensory impairment)? If so,
 - has it made the person unable to make the decision or decisions in hand?

For the purposes of the 2000 Act a person is unable to make a decision for him/herself if, due to mental disorder or inability to communicate because of physical disability, he/she is incapable of

- acting; or
- making decision; or
- communicating decisions; or
- understanding decisions; or
- retaining the memory of decisions.

The Act does not explain how to assess capacity, but any one of the above elements may be critical depending on the decision in hand. The next section looks at the implications for practice of each of the above criteria or 'tests'. For further detailed discussion see ward³.

³ Adrian D Ward LL.B, Adult Incapacity (W Green, 2003), para 1.28.

APPLYING THE CRITERIA

Understanding the information relevant to the decision

- 7 First, you need to be clear about the decision or decisions to be made and what the options may be. The next step is to consider carefully how best to put across relevant information for the person concerned. Such information will include:
- the action or decision needed;
 - why the action/decision is needed;
 - the likely effects of making the decision;
 - the likely effects of not making the decision; and
 - any other choices or options open to the person.

How information is given will affect the ability of the individual to understand. Use broad terms and simple language (or other method appropriate to the person) to explain the proposed action or decision. It will not always be necessary to explain everything in great detail.

What do we mean by 'understand'?

- 8 There are two strands to 'understanding'
- there is having a grasp of the facts; and
 - the ability to weigh up the options and foresee the different outcomes or possible consequences of one choice rather than another.

Factual knowledge base

- 9 The key here is the individual's awareness of his/her personal and financial circumstances. For personal care this would mean probing the person's knowledge of his/her living arrangements, safety and health care needs. For financial assessments, questions will be about the person's understanding of his/her assets, outgoing expenses and financial obligations.

For example:
someone with mild dementia may remember the name of his/her bank and approximate savings but could easily be confused by discussion around various options for safeguarding his/her assets against the effects of forgetfulness.

It will be important to know whether the person has the information needed to make a specific decision.

Understanding the options - use and weigh up the information as part of making the decision - being able to act on the decision.

- 10** Faced with choices, a person should be able to understand and weigh up information about options and any risks involved – and act on the decision made. You should be aware that in certain cases, an adult may be able to understand the information, but unable to act on it because of the effect of his/her mental or physical impairment.

For example:
an elderly widow may never have had to deal with money matters because her husband did everything. The person must be given the necessary information in as simple a manner as possible and helped to understand it before assessing her capacity to manage. It may be that the widow will learn to manage with support.

For example:
certain types of disorders, e.g. severe acquired brain injury, cause people who are able to understand and absorb information, to act impulsively, regardless of the information available and their understanding of it.

Unable to communicate the decision (whether by talking, using sign language or any other means)

- 11** The 2000 Act includes people with impaired decision-making capacity due to severe communications difficulties caused by a physical condition such as a stroke or sensory impairment. It could also apply to someone who is unconscious following an accident.

Before concluding that someone is totally unable to communicate and therefore lacks capacity, strenuous efforts must first be made to assist and facilitate communication. It is very likely that in such cases that the specialist skills of a speech and language therapist will be required. Communication by simple muscle movements, such as blinking an eye or squeezing a hand to indicate 'yes' or 'no' may be sufficient to indicate that the person has some capacity. Whether it is possible to probe understanding and level of understanding will depend on a number of factors. In some situations a psychological assessment to test complexity of reasoning may be required.

Retain the information relevant to the decision

- 12** The person may be able to understand their circumstances and able to make a decision but not able to remember all relevant information due to short-term memory loss. This should not automatically mean that the person is incapable of making the decision in hand. Aids such as videos and voice recorders could be used to support the person's memory, and record his/her responses. You may need to talk with the person several times to go over the information and to see if his/her response is consistent (even if the person cannot remember having been asked before). If the person's response is consistent then this may be taken as a signal that he/she has sufficient capacity to understand the decision in hand.

Chapter 2



SUPPORTING DECISION-MAKING

Introduction

- 1 A person should not be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.

There are a number of ways to help and support someone to make his/her own decisions. These will vary depending on the decision to be made, the timescale for making the decision and individual circumstances of the person wishing to make it.

The 2000 Act applies to a wide variety of people with a range of conditions which may affect their decision-making capacity. Different methods apply when seeking to give appropriate explanations, help and support, for example, to a person with a learning disability, dementia or a severe acquired head injury.

It is important to note that the individual's capacity to make decisions at a particular time is likely to be compromised if he/she is suffering pain or discomfort, is taking medication which causes drowsiness, or has a short-term illness.

Some pointers are given below – only some of these will be relevant to any particular situation and the examples are not exhaustive.

Providing all relevant information

- 2 The provision of relevant information is essential for any type of decision-making, no matter how simple the decision or capable the decision-maker. The goal is to enhance communication and understanding so the person is informed. All practical steps must be taken to help the person make the decision themselves. This includes providing all the information relevant to the decision in question in a way the particular individual can understand. It is important to choose the means of communication that is easiest and most appropriate for the person concerned.
- Take time to explain anything you think might be relevant or might help the person make the decision in question.
 - Try not to burden the person with more information than is needed. An explanation in broad terms may be sufficient for the decision to be made.
 - Describe any foreseeable consequences of making the decision or not – the risks and benefits.
 - Explain the effects the decision might have on the person and on others close to the person.
 - If there is a choice, give the same information in a balanced way.

Communication: general points to consider

- 3 The following points will apply to the majority of situations:
- consult family members, care workers or whoever knows the person well on the
 - most effective way or method of communicating with the person concerned;
 - best times to communicate; and
 - best people to be involved in doing this.
 - Use simple language and where possible use pictures and objects rather than words.
 - Ask one question at a time (avoid asking multiple questions in the same sentence).
 - Speak at the right volume and speed.
 - Use language appropriate to the individual (words and sentences).
 - Be aware of cultural or religious factors which might influence the person's way of thinking, communicating and behaving.
 - Consider whether the services of an independent advocate (if the person does not have one already) might be helpful in assisting communication.

Communication: aids for people with specific communication or cognitive problems

- 4 A wide range of aids has been designed to assist communication, the key is to find out what will best meet the needs of the individual.
- Find out what the person is used to – for example Makaton or some other way of communicating that is only known to those who are close to the person.
 - If the person has hearing difficulties, consider using appropriate visual aids or sign language.
 - Consider using any appropriate mechanical devices such as voice synthesisers or other computer equipment.
 - In cases where you are unsure how best to assist, consider seeking professional help from, for example, a speech and language therapist or expert in clinical neuropsychology.

Choosing the best time and place

- 5 Most people find it easier to make decisions when they feel relaxed. A person's state of mind and ability to make a decision, can be influenced (amongst other things) by the physical environment. It is also important to recognise that some people are more alert or able to pay attention better at different times of the day.

Taking practical considerations into account, you will need to judge which of the following factors will be important in each situation.

Location

- Where possible, choose the best location where the person feels most at ease – usually people will say that they feel more comfortable in their own home, or may prefer somewhere neutral, rather than in a doctor's surgery or interview room.
- Consider if it might be easier to make the decision in a location relevant to the decision – for example – a decision to consent to attending a day care centre or a move to a care home may be made easier by a visit (which would in any case be good practice). Where the person has no previous experience on which to base a decision, he/she may need to be given the opportunity to gain direct experience before he/she can make an informed choice or commitment to a specific decision.
- Choose a quiet place where interruptions are unlikely. Try to eliminate background noise or other distractions.

Timing

- If possible, try to choose the time of day when the person is most alert.
- Take one decision at a time – be careful to avoid tiring or confusing the person.
- Don't rush – allow time for reflection or clarification as appropriate.
- Be prepared to abandon the first attempt and try at other times.
- If the person's capacity is likely to improve, for whatever reason (for example, after treatment), if possible wait until it has done so. This may not be possible if the decision is urgent.
- Some medication could affect capacity (e.g. medication which causes drowsiness or affects memory). Consider delaying the decision until any negative side effects of medication have subsided.
- When someone is in an acute state of distress e.g. following bereavement, or where there are long-standing issues influencing the person's understanding, decision-making may be delayed to give him/her the opportunity to recover/undertake a recognised psychological therapy.

Enabling decision-making

- 6 In addition to doing all you can to create the best possible environment to present relevant information for decision-making, there are other techniques and support mechanisms which may assist.
 - Many people find it helpful to be able to talk things over with someone they trust or with people who have been in a similar situation. For example, people with a learning disability may benefit from the help of a designated support worker or being part of a support network of peers.
 - It may be helpful for the person to have assistance from an advocate who is independent of family and other agencies involved in the person's care. An advocate could help the person express their views, choice/s and aspirations. (Person-centred plans can map out people's wishes, hopes and aspirations in advance of a crisis or change in ability or circumstance.)⁴

Publications, DVDs and other materials have been produced to help people who need support to make decisions, and for those who provide support. (See Appendix 3 Useful Resources.)

⁴ British Institute of Learning Disabilities, Fact Sheet – person centred planning. www.bild.org.uk

Chapter 3



ASSESSING CAPACITY INTERVIEW: MONEY AND PROPERTY MATTERS

This chapter provides an outline for conducting an interview to assess the capacity of a person with mental disorder or inability to communicate in relation to the management of his/her money and any other assets.

Steps to take

Step 1:
Explore the factual
understanding of
present financial
circumstances

One reason for starting the capacity interview with a review of the person's understanding of his/her finances is to establish whether or not the **power of attorney** option remains open. A person may be capable of appointing someone to be their attorney and give instructions about how his/her money is to be spent, but at the same time lack the capacity to manage his/her money.

If the person lacks capacity to appoint an attorney and there is evidence that he/she is unable to manage their financial affairs, it will be necessary to consider what type of intervention will be most appropriate to the circumstances of the individual (and taking account of the principles of the Act). (See Appendix 4.)

- Find out the person's previous role in money management.
- Explore and record the person's knowledge of his/her assets, income, expenses, debts and financial dependents (if there are any).
- Accept approximations and only seek information on major income sources/debts.

- If the person does not volunteer the information about significant aspects of his or her financial status, then gently prompt. If acknowledged, inquire at a later point to see if the information has been retained.
- Probe for reasons behind any discrepancies between the self report and the records or third party report.

If you are assessing capacity for routine money management, it is reasonable to expect the person to show a basic awareness of his/her financial circumstances. He/she should also be able to show a basic understanding of using a cheque book or bank card/or managing in the way they always have. Bearing in mind some people will view such questions as an infringement of their privacy – the person may need to be reminded of the reason for the questions.

Specifically the person should be able to say roughly what

- his/her weekly or monthly income is;
- his/her weekly or monthly expenses are; and
- what he/she has by way of savings.

Points to consider

- Is there a discrepancy between the person's understanding of his or her actual income and expenses that cannot be put right through learning?
- Can the person be helped to develop skills to manage his or her money, e.g. learn to count change, understand regular weekly expenditure, learn to sign a cheque and use a bank machine?
- Does the person have a basic understanding of money and its value, e.g. coin recognition and worth; decipher a bank statement; recognise a cheque book (provided they have been familiar with these in the past).
- Is the person able to estimate the approximate worth of his/her various assets (if there are any, e.g. property/shares)? If managing large sums of money, can he or she appreciate the size of the estate in terms of purchasing power?
- Is the person aware of obligations to financial dependants? (where appropriate).

Step 2:
Identify areas of
unmet financial
need

Not all of us can understand the complexities of stocks and shares and the management of larger investments but we can choose to delegate and to supervise activities as well as redress any improper action if it came to light. The same cannot be said of the person who because of significant cognitive impairment is open to exploitation if safeguards are not in place.

It will be informative to contrast the 'self report' with observations from others. Where discrepancies of information exist, these should be flagged up for further investigation.

Points to consider

- Does the person admit to any problems with routine or complex money management skills?
- For those areas the person acknowledges as problematic, does he or she seek appropriate help?
- Is there any evidence of a recent change in the ability of the person to manage his or her finances?
- Can the person recognise situations of potential exploitation and respond accordingly?
- Can the person communicate his/her financial needs to others to obtain the necessary assistance?
- Does the person face financial risks because of pervasive memory problems?
- How does the person reconcile his/her perception of reality of financial management against objective evidence of inability?
- Does the person recognise that he/she may not be able to implement decisions without help?

Step 3:
Explore
decision-making
within critical areas
of unmet need

Try to find out the degree of insight the person has into the problem areas. First ask them about the concern raised by others.

Engage in decision-specific questions that probe recognition and appreciation of the options to deal with the problems. Explore factual understanding, what they think the options are and advantages and disadvantages of each – and what their decision would be. Look at the chain of reasoning. It may also be instructive to look at the person's history, the sorts of choices they made.

Points to consider

- Is there evidence of stability of choice over a reasonable period of time? Does the person express same choice when questioned on separate occasions?
- Is the person's appraisal of risk realistic? Are major negative consequences overlooked in favour of minor beneficial ones?
- Is there any evidence of rational manipulation of information or the weighing of advantages/disadvantages as part of the deliberation process?
- Even if the person is unable to articulate reasons for his or her choices, are these consistent with his or her values and beliefs?
- If the person is refusing care, is this because of, for example, pride, prejudice or fear? If so, do they understand the consequences of not having care?

Chapter 4



ASSESSING CAPACITY INTERVIEW – PERSONAL CARE

This chapter provides an outline for conducting an interview to assess the capacity of a person with mental disorder or inability to communicate in relation to his/her personal care.

Steps to take

Step 1:
Explore the factual
understanding of
current personal care
circumstances

Talk to the person about his/her

- current living arrangements;
- own view of their health; and
- recollection of informal help and formal services received.

If the person does not mention relevant facts, bring these to his/her attention. If acknowledged, inquire at a later stage to see if these have been retained. Probe for the reasons behind any significant discrepancies between self reporting and third party reporting. It is presumed that you will know in advance where the person lives and if they live alone/with someone, and the availability and acceptance of supports.

Points to consider

- Is there a substantial discrepancy between the person's description of his/her daily routine or current living arrangements and that known or reported by others?
- Is the person aware of his/her responsibilities or obligations to dependants? (if appropriate).
- Is the person aware of the important decision-making demands faced in meeting personal care needs?

**Step 2:
Identify areas
of unmet need in
each personal care
domain being
investigated**

Talk with the person about self care, i.e. ask what he/she does to look after themselves and how well the person thinks he/she manages. The aim is to explore whether the person has the skills and knowledge to meet his/her personal care needs. If not, does the person recognise his/her limitations and seek appropriate assistance?

It will then be helpful to compare the person's self assessment with reports from others on how he/she manages on a day-to-day basis. If it is not possible to form an opinion about how well the person is functioning in essential areas, it is advisable to arrange for an additional occupational therapy assessment.

Points to consider

- Does the person admit to any problems in meeting personal care needs? If so, does he/she seek appropriate assistance?
- Is there evidence of recent change in the person's ability to self-manage? For example, has there been a deterioration in his/her appearance, self care, living environment – house less clean and tidy than before, lack of food in the cupboard, etc.
- Can the person recognise risky situations and respond accordingly?
- Could the person ask others for help in an emergency?
- Does the person encounter safety or physical health risks because of memory problems?

**Step 3:
Explore
decision-making
within critical areas
of unmet need**

Areas of unmet need in terms of the person's personal care will be identified through the assessment and review process. The next stage will be to explore the person's ability to make decisions in relation to how these might best be met.

- First, ask questions designed to uncover the degree of insight the person has in relation to his/her self-care limitations. Begin by asking the person about any concerns raised by others who know the person well.
- Secondly, ask the person specific questions to test their 'understanding and appreciation' of the choices available. You may need to probe to assess: how far the person is able to weigh up the advantages and disadvantages of one option over another; whether or not the person can anticipate the consequences, both in terms of likelihood and severity. If the issue is refusal of services, explore fully the person's appreciation of the foreseeable consequences.

- Thirdly, look for evidence of reasoned choice. Examine the chain of reasoning for logical consistency. This is especially important where the person seems to be making an irrational or illogical decision that may have an adverse impact on his or her personal care, physical safety or well-being. You may need to probe his/her choices that seem to be predicated on delusional beliefs or hallucinatory experiences. A review of previous actions, prior wishes or history of choice under similar circumstances may provide information that either justifies or challenges the present choice or preference being expressed.

Points to consider:

- Is the person able to understand crucial information relevant to making decisions about his or her particular personal care needs?
- Is the person able to remember crucial information and/or is there evidence of consistency of choice over time?
- Can the person say what is likely to happen if his/her personal care needs are not met? Is the person's assessment realistic? Is he/she focussing on possible minor consequences and overlooking major ones?
- Are the person's stated reasons for his/her choice relevant to the decisions in hand?
- Are the persons actions or choices consistent with his/her expressed goals and priorities?
- Even if the person is unable or refuses to articulate the reasons for his/her personal care choices, are actions consistent with his/her expressed values or beliefs?

Chapter 5



PERFORMING CAPACITY ASSESSMENT WITH SPECIFIC CARE GROUPS

- 1 This chapter looks at six major groups of people who may have impaired capacity to act or make some or all decisions for themselves.
 - People with neurological conditions
 - People with dementia
 - People with a learning disability
 - People with a severe or chronic mental illness
 - People with alcohol related brain injury
 - People affected by a severe stroke
- 2 The first question to consider is whether there is the necessary expertise and experience within the team to communicate with and assess the capacity of the adult to make the decision/s in hand or whether it will be helpful to seek specialist involvement.

People with neurological conditions

- 3 People with neurological conditions, whether organic or caused by injury, whether progressive or stable, can present with challenging and complex capacity issues. They may proceed through stages of deterioration and/or recovery. This has implications for the timing of the capacity assessment as well the need for a periodic review of capacity. It may be advisable to request a neuro-psychological or specialist assessment. (A variety of batteries of tests are available sensitive to cognitive dysfunction for different conditions).

Implications for assessment

Rarely neurological disease can manifest as a result of changed genetic coding, e.g. Huntington's Disease (HD). When assessing the capacity of people with hereditary conditions it is crucial to have some appreciation of the familial impact of living with the disease and the severe health challenges whole families face.

Factors which influence a person's capacity with a neurological condition may include

- Apathy
- Agitation
- Attention deficit
- Anxiety/panic disorders
- Irritability
- Rigid thinking
- Denial (which may be truly organic)
- Inability to put events in order of importance
- Reduced capacity to organise information
- Paranoia, depression, psychosis and other mental health problems
- Disinhibited behaviour
- Grief (as a result of the many losses individuals experience)
- Controlling impulses
- Controlling feelings
- Impaired judgement

- Monitoring self awareness
- Creative thinking
- Problem solving
- Visual/spatial abilities
- The ability to begin and end activities
- Problems with memory. It is critical to differentiate between the ability to learn from the ability to remember. Typically individuals with ‘true’ memory problems have difficulty with the latter – remembering. Many people with neurological conditions, e.g. Huntington’s Disease (although frequently referred to as a dementia) do not have a primary memory deficit.
- Sleep disturbance
- Motor impairment
- The effects of medication
- Certain neurological conditions produce changes in personality, e.g. hostility, suspiciousness, drive, apathy or emotional control (rage, agitation, disinhibition) that can be either associated with or independent of changes in cognition. However, not all psychopathology is associated with the result of neurological disease.

Typically these changes are a result of changes that take place in the brain, but the environment (including people, events, health issues) can also influence the assessment of capacity, e.g. when a person with HD has an infection this can markedly increase their incapacity cognitively, mentally and physically.

Communication for people with neurological impairment is often compromised as it requires a complex integration of thought, muscle control and breathing. All three of these functions may be impaired. As a consequence articulating and initiating conversation, organising what needs to be said requires knowledge of the individual and careful preparation. Understanding what is being said to you may be difficult to interpret.

Communicating effectively - Huntington's Disease

In addition to the general points on communication made earlier in this guide, the following approach is advised in relation to people with Huntington's Disease:

- be calm, gentle, matter of fact and relaxed;
- use touch to show that you care;
- build trust by starting initial communication socially;
- use good eye contact and try to be at eye level;
- keep rate pitch and volume of speech low as easier to hear;
- set up appropriate communication aids before communication becomes difficult;
- listen actively. If you do not understand apologise and ask the person to repeat it. Repeat back and rephrase what you hear so that the person knows what parts you understood and what needs repeated;
- respond to the emotional tone. If the person sounds upset acknowledge those feelings even if you cannot decipher the words;
- praise and encourage all efforts.

People with dementia

- 4 People with dementia should not be assumed to be incapable of making decisions. In the early stages, intellectual deterioration may not have progressed sufficiently to affect their ability to make decisions. However it will be important to discuss future decision making with them, including the benefits of appointing someone with power of attorney, whilst they are still able. Points to consider:
 - People with dementia may have fluctuations in their cognitive functioning over a day or several days, so timing for a capacity assessment while the person is functioning well will be important.
 - People with dementia (the majority of whom are 75+) will have long history, both personal and medical, that will influence their response to their present circumstances.
 - Cultural diversity amongst elderly people is very significant. Cultural, including religious and gender norms and family traditions may be very different and have a profound effect on everyday decision-making.

- There is an increased prevalence of medical problems in older people. Fatigue, decreased concentration, poor hearing and diminished eyesight may result from conditions that are far more prevalent in older people. Many of these conditions are treatable and will influence communication and ability to be involved in decision-making.
- Older people may not have experience of dealing with statutory authorities and may be particularly anxious about the formal assessment processes and resent any involvement from other agencies.
- Older people may be especially concerned about others trying to force them out of their home and into an institution.

Implications for assessment

- In assessing the capacity of someone with dementia it may be necessary to involve a specialist clinician to understand how information processing deficits may affect decision-making capacity. For a person over 65 this could be a psychiatrist in old age or for a younger person a neurologist; or a clinical psychologist in this specialist area.
- The professional carrying out the assessment will need to determine if the person's preserved intellectual and information-processing abilities are sufficient to support reasoned decision-making with respect of their current situation. He/she will also need to assess the person's ability to follow through on his/her stated intentions. Potential issues may include: self-control, planning and self-reflection, which may undermine the person's stated intentions, and may interfere with his/her ability to appreciate the consequences of his/her actions.
- Staff involved with making an initial assessment will need to use their judgement on whether to involve a specialist medical practitioner with knowledge of how a diagnosis may impact on mental functions. It is important to recognise that brain damage/dysfunction does not impair decision-making in a uniform fashion. The decision-making process can be affected at different levels or in different ways.

People with a learning disability

- 5 Because someone has a diagnosis of learning disability, this must not undermine the presumption that he/she has decision-making capacity. Characteristics associated with specific syndromes cannot be presumed to be evidence of incapacity, e.g. in Down's Syndrome, there is an extensive range of ability. Similarly difficulties in communication should not be confused with incapacity.

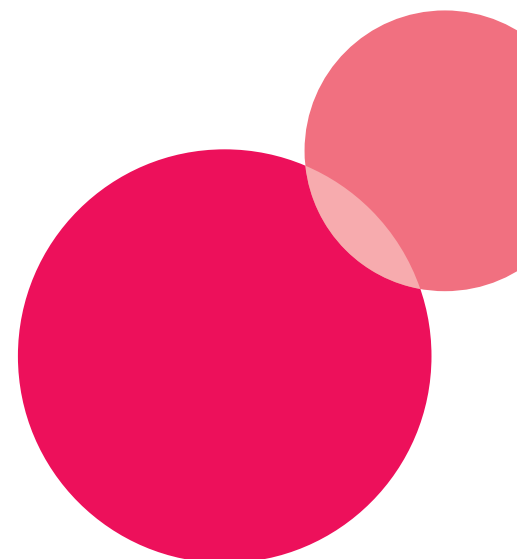
Factors to consider in carrying out an assessment of capacity

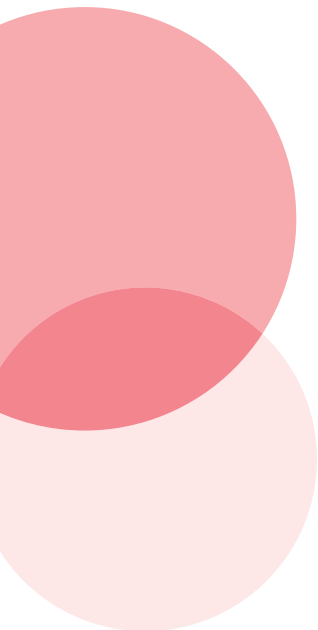
Decision-making skills may be under-developed as a consequence of the limiting experience of restrictive environments, e.g. institutional, over-protectiveness or other externally imposed barriers to growth and development, including sometimes negative expectations of progress by professionals. The importance of applying the fifth general principle under the Act is crucial here whether or not it is decided that an intervention under the Act is needed: 'in so far as it is reasonable and practicable to do so, encourage the adult to exercise whatever skills he/she has concerning his/her property, financial affairs or personal welfare, as the case may be, and to develop new skills'.

Implications for assessment

- It is important to recognise the limitations of generic cognitive tests in assessing the capacity of people with a learning disability (and others), in relation to the specific decision in hand. A low score can be misleading. The importance of the needs assessment cannot be over stressed. Specialists in the field will know what the most up-to-date knowledge, supports and services are available to assist people with a learning disability in communicating and making decisions.
- People with a learning disability, particularly those who have been institutionalised, may have had greater than usual exposure to assessments of various kinds. There may be resistance to yet another intrusion by an authority figure. Alternatively, behaviour conditioned by the need to survive in the system may result in total compliance and a need to provide the assessor with the expected response. There may be anxiety in the face of the threat of loss of autonomy.

- In addition to the above, life experience is likely to be lacking for someone who has spent many years in institutions, and as a consequence his/her ability to make informed choices will be severely limited. The solution to this is to offer opportunities to experience situations relevant to proposed changes. Staff involved with assessments should have an understanding that these factors that may affect the person's responses and mask their real abilities. Every effort must be made to empower the person to express his/her views and wishes.
- You will need to be aware of the most appropriate way to communicate with the individual, including use of particular words and phrases, the use of talking-mats, etc. Be careful to put forward one idea or question at a time and give plenty of space for the person to consider his/her reply.
- You will need to be alert to the double standards and prejudice that can still sometimes be present against people with a learning disability, by others who may be part of the assessment process. Some individuals will have been prevented from making decisions for themselves because this may have been perceived as harmful in some way, thereby omitting the opportunity for the person to make and learn from mistakes as most of us do.
- You need to be alert to the fact that not all parents and family members are involved closely with the person, particularly when the person has been institutionalised. The family's perceptions of the person's capacity and their expectations for the person may be at odds with those of others who are in day to day contact with the person. Again independent advocacy can help.



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- Those involved in assessing the capacity of someone with a learning disability should be aware of the impact that different factors can have in leading up to a crisis which may have precipitated the need for assessment under the 2000 Act. For example, the lead-up to an apparent crisis may have been intolerance or rigidity on the part of staff or care-givers with respect to autonomy in less critical situations. Escalation of the situation might have been avoided by more reasonable responses to the initial incident. For example, treating an expression of frustration as non-compliance and imposing further controls, leads to an increase in frustration, possibly violence and stricter control, e.g. guardianship. Modification of environment and assistance with stress or anger management may have been all that was required.

People with severe or chronic mental illness

6 Factors to take into account in assessing capacity

- Stigma in relation to mental illness is still a big issue in the community. You should be sensitive to the fact that the person may feel especially stigmatised by the assessment process and do all you can to help the person to feel empowered in the situation.
- Psychiatric disorders as such do not automatically imply incapacity in any area of decision-making.
- Delusions (fixed false beliefs) as such do not imply impaired decision-making (unless the delusion is in respect of the decision to be made).
- Individuals who are hallucinating (hearing voices, seeing things which are not there) may find it hard to concentrate as they may be easily distracted by the hallucinations.
- Individuals with depression may find it hard to concentrate during the assessment; depression itself may dramatically impair concentration.
- Individuals with depression may have trouble seeing the potentially positive outcomes of changes in their current situation and may refuse all help.
- Individuals who have been treated with some drugs, such as neuroleptics, may present with physical symptoms and these should not be confused with the capacity to make decisions. The effects of a heavy dose of neuroleptics may make the person sleepy, lack concentration, and have difficulty articulating.
- The person's capacity to act and make decisions may fluctuate with changes in his/her condition.
- Other mental disorders may impair judgements, e.g. those with mania may have an unrealistic understanding of their abilities.

Implications for assessment

- It is important not to assume that because someone with a mental disorder he/she cannot adequately discuss the issues in hand.
- It is important to try to understand how the mental disorder affects the individual – remembering that capacity is being assessed only in relation to the particular matters in hand. Only those areas being assessed are particularly important. Delusions or misperceptions resulting from the mental disorder are only relevant if they relate to the issues in hand, e.g. specific delusions about money matters.
- You may need to proceed slowly to ensure that the person can concentrate and focus on the issues in hand. You may need to see the person over several visits to get to know them and begin to understand the ‘person’ in relation to the disorder.
- You should consider the person’s mental state in relation to the effects of short-acting sedation or recent medication changes and whether to delay assessment until a more appropriate time.

People with alcohol related brain injury

- 7 Alcohol related brain injury is associated with a change in thinking and memory abilities. It affects the way people learn and understand new information and how they communicate with others. You can help people with alcohol related brain injury improve their communication skills by keeping the discussion focused and checking that they have understood what has been discussed.

Keeping the conversation focused

People with alcohol related brain injury often have difficulty with focusing on a topic of conversation. They can be easily distracted by less relevant points of discussion and wander off in other directions. You can get them back on track by:

- reminding them of the conversation topic;
- redirecting the conversation by repeating a question;
- using a pencil and paper to focus discussion.

Communicating effectively

Keep the following points in mind when giving instructions or information:

- use concrete and familiar terms;
- break down information into small important points;
- slow down when you talk; and
- focus discussion on one topic at a time.

Beware of assuming people with alcohol related brain injury are understanding and remembering what is being discussed. Some people may nod their head and say they understand when in reality they don't. It is a good idea to check their understanding and retention of information by asking the person to repeat what you said in his/her own words.

Dealing with memory and retrieval problems

Many people with memory problems linked to alcohol related brain injury respond best to closed rather than open ended questions. That is, it is easier to respond to questions where they can provide a 'yes' or 'no' answer. For example, instead of asking, 'What did you do today?' ask, 'Did you go out today?' Communication can also be improved by providing cues or prompts to trigger memory.

Consider how you appear to the person

When you are trying to communicate clearly and get a message across it is important to consider how you appear to that person. The person with alcohol related brain injury needs to feel comfortable with you and feel that you understand his/her needs and frustrations. You should aim to be non-threatening and non-judgmental.

Things to remember

- Keep conversations focused and on track.
- Give prompts or cues to trigger memory.

Check understanding of information by asking the person to repeat what you said in his/her own words. Be non-threatening and non-judgmental.

People affected by a severe stroke

- 8 Difficulty in communicating does not mean the person has impaired intellect.
- Remember the person may have more difficulty on some days than others, particularly if they are tired, upset or under pressure.
 - Remember that communication is more than just words – watch and listen to how something is being communicated.
 - Try to establish a reliable ‘**yes**’ and ‘**no**’ between you. Remember **gesture** may be more reliable than speech.
 - Speak slowly and clearly at normal volume.
 - Use short sentences keeping language simple and offering choices when asking questions.
 - Encourage the use of simple gestures, thumbs up or down, pointing, miming. Be prepared to support your own speech with simple gestures too.
 - Keep pen and paper handy for you and the other person to use.
 - Writing and drawing might be helpful – write down important words to help focus the conversation.
 - Write down choices to help the person pick the right words.
 - Encourage the person to try to write – even a couple of letters may help find the word he/she is searching for.
 - Ask for repetition especially if someone’s speech is slurred or indistinct.
 - Clearly indicate when you have understood – use facial expressions and intonation to support your speech when conveying meaning, understanding and encouragement.

Appendix 1



SAMPLE INTERVIEW QUESTIONS – MONEY AND PROPERTY

Please note that the following are examples only and questions will need to be tailored to the circumstances of each individual.

1. Factual understanding

Can you tell me something about your present money situation?

Where do you get your money from?

Do you get a pension? Salary? Roughly how much?

Do you have some savings? If so roughly how much?

Do you own your own house?

Do you have any debts or owe people money?

Do you have any children that re not yet fully grown-up and independent?

2. Areas of unmet need

Do you have any problems handling small bills?

Do you have any problems balancing your cheque book?

Do you manage without help?

In managing your money what different types of things do you do or watch out for? (pay bills, do banking, budget for major purchases).

Have you noticed any problems with your memory that cause you to lose track of time or forget to pay your bills on time?

Do you think you may be pressured into buying things that you don't need or making loans or gifts you really shouldn't because you find it hard to say no or find it difficult to think things through?

3. Where concern exists about inadequate functioning

i) Insight into problem

Has anyone in your family expressed concern to you about how well you are able to manage or keep track of your affairs?

You might want to introduce what you know, e.g. your daughter thinks you don't keep a careful enough watch on your money and that you won't remember to pay your bills on time. Has this ever happened?

ii) Decision-specific probing

You have refused to accept your family's offer to help, or to make a power of attorney. Why? What do you think might be the disadvantages? What might the advantages be?

What are the likely consequences of your choosing to do X? Do you think it very likely that things will turn out the way that you want?

iii) Reasoned choice

Can you tell me why you want to give your money to Fred when he calls?

What happens when you don't have any money for yourself – for your food?

Appendix 2



SAMPLE INTERVIEW QUESTIONS – PERSONAL CARE

The following are examples only, questions will need to be tailored to the circumstances of the individual.

1. Factual understanding

- Where do you live?
- Does anyone live at home with you?
- Are there relatives or friends nearby?
- Can you say who they are?
- How often do they visit?
- Who does your cooking/shopping/cleaning?
- Do you have any health problems?
- Do you see the doctor often?

2 Areas of unmet need

- You told me you get your meals. Do you have any problems with cooking or using your stove? Have you lost any weight lately?
- If you had a bad fall, how would you get help?

3 Where there is concern that functioning may be inadequate

i) Insight into problem

Your family is worried because you got lost twice last month. Do you remember what happened?

Have you been able to care for yourself lately as well as you would like to?

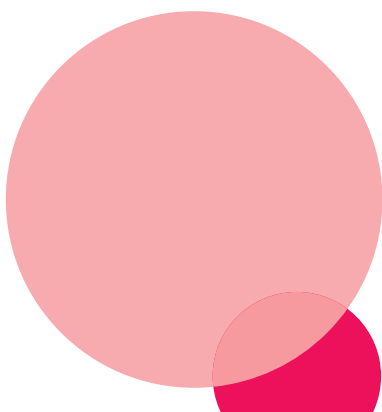
What has happened? Why is your wife so worried about your health?

ii) Decision-specific

You won't allow someone to come into your home and help you with your bath/dressing. What could happen to you if you can't keep yourself or your clothes clean?

iii) Reasoned choice

Why are you sitting in the dark every evening and not putting on the light and the fire now that it is getting so cold?



Appendix 3



USEFUL RESOURCES

- 1 Irenka Suto, Isabel Clare and Anthony Holland (forthcoming August 2007) **Financial decision-making**. National Institute on Learning Disability. www.bild.org.uk

This guide sets out to promote good practice in the area of financial decision-making. It provides a framework that will help those who support men and women with learning disabilities in thinking through difficult situations involving financial decisions and making judgments that are ethically and legally defensible. It contains structured guidance to maximise independence, with examples of practical, research-based, materials to explore understanding of basic financial concepts and contribute to formal and informal assessments of financial decision-making ability. Suggestions are also made to develop the decision-making abilities of people with learning disabilities and enable those who are unable to make one or more financial decisions for themselves to participate as fully as they can in the management of their money.

The guide has been written for health and social care practitioners, managers in social care provider organisations, social care regulators, support workers, family carers and others who are concerned about the well-being of men and women with learning disabilities. It is also a resource that can be used to complement training courses in health and social care.

- 2 Lawton, Annie (2006) **A Voice of Their Own. A toolbox of ideas and information for non-instructive advocacy.** British Institute on Learning Disability.
ISBN 1-904082-98-X www.bild.org.uk

This toolbox is particularly useful for anyone advocating for a person with high support needs by which the authors mean ‘anyone who does not communicate using words, has significant barriers to communication and/or complex physical, health or emotional needs and requires lots of extra support as a result. This could include people who have a learning disability with sight or hearing difficulties or those with a mental illness or autism’.

- 3 Paulsen, J. S. (1999). ‘Understanding Behaviour: A practical guide for individual’s families and professionals coping with Huntington’s Disease’. pp 25-26, Huntington Society of Canada. www.hsc-ca.org
- 4 Silver, K (2005) **Assessing and Developing Communication and Thinking Skills in People with Autism and Communication Difficulties. A Toolkit for Parents and Professionals.** Jessica Kingsley Publisher. ISBN 978-1-843-10-352-3
- 5 National Institute on Deafness and Other Communication Disorder. **USA Autism and Communication**
www.nidcd.nih.gov/health/voice/autism.asp
- 6 Mencap, **Fact Sheet: Communication and People with a Learning Disability.** www.askmencap.info/IFM.GenInfo.nsf

- 7 **Assessment of Capacity in Adults** – Interim Guidance for Psychologists. April 2006. The British Psychological Society Professional Practice Board.
www.bps.org.uk/e-services/find-a-psychologist/expertwitness.cfm
- 8 Scottish Executive: **DVD ‘Making Decisions – Your Rights’** (2006) This DVD comes in two versions – for people with dementia and for people with a learning disability. It sets out how the Adults with Incapacity (Scotland) Act can help and what a person’s rights are under the Act. It presents a series of short ‘mini’ programmes looking at money, health and decisions about your life. The DVD pack includes a booklet about how to use the DVD. It is designed to be used one to one or with small groups. Available free from the Scottish Government telephone: 0131 244 3581 or from Blackwell’s Bookshop.
- 9 Darzins P et al (Ed) **Who Can Decide? The six step capacity assessment process**. Memory Australia Press. 2000 ISBN 0-646-40343-5.
- 10 Joint Centre for Bioethics – **Aid to Capacity Evaluation (ACE)**
www.utoronto.ca/jcb/disclaimers/ace.htm. The purpose of ACE is to help clinicians systematically evaluate capacity when a patient is facing a medical decision. The ACE may be copied by any person for non-commercial use.
- 11 Highland Health Board and Highland Council – Joint Good Practice Guidance on Assessment of Capacity.
www.highland.gov.uk

- 12** Ward, Adrian D., **Adult Incapacity**. W Green 2003. ISBN 0-414-01472-3

This is the key reference book on the Adults with Incapacity (Scotland) Act for lawyers and other professionals working closely with the Act. It provides detailed discussion of issues relating to the formal assessment of capacity.

- 13** Patrick, Hilary, **Mental Health, Incapacity and the Law in Scotland**. Tottel Publishing, 2006. ISBN 1-84592-062-7

This is a comprehensive guide to the Adults with Incapacity (Scotland) Act 2000 and Mental Health (Care and Treatment) (Scotland) Act. It is an essential handbook for agencies and professionals involved with providing information, support and services to adults with mental disorder and their carers in Scotland.

Appendix 4



ADULTS WITH INCAPACITY (SCOTLAND) ACT: PROVISIONS AND PRINCIPLES

1 How the Act can help

The Act provides the following ways for managing and safeguarding a person's welfare, financial affairs or both:

Powers of attorney – this is a means by which individuals, whilst they have capacity, can grant someone they trust powers to act as their continuing (financial) and/or welfare attorney, in case capacity is lost at some future point. One or more persons can be appointed.

Access to Funds scheme – this is a way of accessing the adult's bank or building society account in order to meet his/her normal living costs. An application can be made to the Public Guardian by an individual or organisation. The person or organisation appointed is called a 'withdrawer'.

Guardianship order (welfare and/or financial) – may be applied for by one or more individuals acting together or local authority and granted by the sheriff. This is appropriate where the person requires someone to make specific decisions on their behalf over the long term. Financial guardianship may be appropriate where the person's finances are complex.

Intervention order (welfare and/or financial) – may be applied for by an individual or local authority and granted by the sheriff to carry out a one-off action or to deal with a specific issue on behalf of the adult.

Management of (care home) residents funds – A certificate of authority may be granted to a care home manager by the supervising body (local authority or health board) where the resident lacks capacity to manage his/her own funds and there is no other individual willing or able to do so.

Medical treatment decisions – a doctor is authorised to provide medical treatment and care to someone who is unable to consent, subject to certain safeguards and exceptions.

2 Principles to be applied

The following principles must be applied when deciding whether a measure under the Act is necessary and if so, which will be the most appropriate to meeting the needs of the individual. The principles must also be applied by anyone appointed with powers under the Act when a decision needs to be taken on behalf of the individual. It is also recognised good practice that the principles should be applied in relation to all decision-making for a person with impaired decision-making capacity, regardless of whether he/she has a proxy under the Act.

Principle 1 – benefit

- any action or decision taken must benefit the adult and only taken when that benefit cannot reasonably be achieved without it.

Principle 2 – least restrictive

- any action or decision taken should be the option that restricts the person's freedom as little as possible but at the same time enables the purpose of the action to be achieved.

Principle 3 – take account of the past and present wishes and feelings of the adult

- In deciding if an action or decision is to be made, and what that should be, account shall be taken of the present and past wishes and feelings of the adult, as far as they can be ascertained. The person should be offered appropriate assistance to communicate their views (for further guidance see Appendix 1).

Note: that it is compulsory to take account of the present and past wishes and feelings of the adult if these can be ascertained by any means whatsoever.

Principle 4 - consultation with relevant others

- In deciding if an action or decision is to be made and what that should be, account shall be taken of the views of: the nearest relative and the primary carer of the adult; the adult's named person⁵; any guardian or attorney with powers relating to the proposed intervention; any person whom the sheriff has directed should be consulted; any other person appearing to have an interest in the welfare of the adult or the proposed action, where these views have been made known to the person responsible – in so far as it is reasonable and practicable to do so.

Principle 5 - encourage the adult to exercise whatever skills he or she has and to develop new skills as far as possible.

⁵ 'named person' means the person nominated (under the Mental Health (Care and Treatment) (Scotland) Act 2003, by the adult to represent their interests or give their support. This is automatically the nearest relative where the person had not named someone else. This will only be the case in relation those adults who come under both the Mental Health Act and the Adults with Incapacity Act.



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