



Supporting People with Dementia to be involved in Safeguarding Enquiries: Toolkits to aid Practice

July 2022

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The information in this document is based on the guidance document produced by Department of Health & Social Care and the University of Bath, “Supporting People living with Dementia to be involved in adult safeguarding enquiries” March 2021

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Policy Summary

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1. Background

The guidance document “Supporting People living with Dementia to be involved in adult safeguarding enquiries” was commissioned in 2019 on behalf of the Office of the Chief Social Worker for Adults. The guidance was researched and completed by Dr Jeremy Dixon, University of Bath.

2. Introduction

It is estimated that 850,000 people in the UK have dementia, with 1 in 14 adults over 65 being affected (Prince et al, 2014). Research has shown that older adults living with dementia are at greater risk of abuse and neglect than those without a diagnosis (Fang & Yan, 2018). Such abuse may include psychological, physical, financial or sexual abuse and can take place anywhere, including the community, care homes or hospitals.

People central to the adult safeguarding process should be involved in the enquiry and be given choices and control about how their case is managed. Dementia can cause difficulties with memory, thinking, language and problem-solving. People living with dementia may find it difficult to report abuse or to make choices about how they would like their situation to be managed. Because of this, thought needs to be given as to how individuals can be supported to make decisions within safeguarding enquiries, in line with the requirements of the Mental Capacity Act 2005.

When a safeguarding enquiry is made, practitioners must consider how the person in question views the alleged abuse or neglect and should ensure that they are central to decision-making. Such decisions involve thinking about risk and making proportionate judgements about it. However, research shows that people living with dementia, carers and professionals tend to interpret risk in different ways and that people living with dementia rarely use the term “risk” when talking about their situation.

3. Suggestions for Good Practice

Providing people with clear information about safeguarding – many members of the public are likely to be unaware of the principles of the Care Act 2014, or what safeguarding means. Local Authorities should provide publicly accessible information which sets out what abuse is and how people can report it.

Thinking about the person’s communication and cultural needs – Dementia is an umbrella terms for several conditions. Because of this people may experience a range of symptoms. It is important to start by assessing the difficulties that an individual experiences and what kinds of help they may find useful. Additionally, a person’s cultural needs may affect the type of support they would find it useful to receive. Checklists can be used to identify these needs. For example, identifying the type of dementia, the method of communication that the person prefers as well as their ethnicity, religious views or sexuality.

Thinking about where the conversation is held – Safeguarding enquiries involve talking to people about abuse and neglect. This is a sensitive issue and so thought needs to be given about where conversations take place.

Building relationships with the person living with dementia – where possible, people who are conducting safeguarding enquiries should work with members of staff who already have an established and trusting relationship with the person concerned. In cases where the person living with dementia is not known to social services, then workers should try and build a relationship with the person over more than one session, where this is possible given the level of risk presented.

Consider advocacy – whilst many people living with dementia will wish to speak for themselves, others will feel reassured if someone close to them can help them to communicate or speak on their behalf. Professionals should include friends or family members if this is what the person wants or should consider a referral to advocacy services where the person is unsupported.

Consider decision-making guides – conversations about safeguarding can be upsetting and are often complex. Because of this, practitioners need to consider how people living with dementia might be supported to take part in discussions, on line with the requirements of the Mental Capacity Act 2005. Decision-guides can help to break down information into chunks and may make it more manageable. For example, such guides can list options in a way that can help individuals to consider the reasons for and against taking different decisions, can identify the extent to which a person may feel pressurised by other individuals and can identify the role the person would prefer to take when making the decision.

Consider how to record the outcomes of safeguarding meetings in an accessible way – meetings which take place as a result of a safeguarding enquiry should be minuted. However, people living with dementia may find it difficult to remember the outcome of a safeguarding decision. Professionals should explore ways of providing reminders to the person about the outcome of the meeting. They should also review their practice to ensure that future services might better address the needs of people living with dementia.



4. Principles for Practice

Human Rights – When considering how to protect people living with dementia from abuse and neglect, we need to begin by considering their human rights. The rights of those living with dementia have often been neglected in the past, due to mistaken assumptions that they lack capacity or are unable to make decisions for themselves (Boyle, 2008).

The following FRIEDA principles (Butchard and Kinderman, 2019) which focus on Fairness, Respect, Equality, Identity, Dignity and Autonomy can be used to remind practitioners how human rights principles should apply to people living with dementia.

Principle	Application to Practice
Fairness	<ul style="list-style-type: none"> • Do not make assumptions about me • Give me time and space • Do not exclude me because of my dementia
Respect	<ul style="list-style-type: none"> • Listen to me • Find out what's important to me • Make a positive effort to get to know me • Speak to me • Look at me when you speak to me
Equality	<ul style="list-style-type: none"> • Give me input into the care I receive • Respect my culture, race and religion • I have a right to intimate relationships • I have a right to vote

Identity	<ul style="list-style-type: none"> • Respect my intelligence • Respect my skills and talents • Respect my choices about how I want to live my life • Let me live my life
Dignity	<ul style="list-style-type: none"> • Do not embarrass me • Ask my opinion • Do not patronise me • If you are helping me, explain what you are doing to me
Autonomy	<ul style="list-style-type: none"> • Allow me to express my views • Respect my personal freedom • Give me the freedom to do what I want, which may involve taking risks • Provide assistance to make decisions for myself • Take my significant others into account • Give me advice but do not try to control me •

Applying a Strengths-Based Approach – Strengths-based approaches are a useful way of supporting the human rights of people who are living with dementia. Workers using this approach should identify things which the person is already successful at and seek to use these strengths. While strengths-based approaches can be used creatively with people living with dementia, individuals may become less able to communicate their strengths and preferences as the condition progresses. In these

instances, workers may draw more on the person's historical will and preferences in line with the Mental Capacity Act 2005.

Considering Culture and Diversity – When considering an individual’s culture and diversity, there are six things that are helpful for workers to consider (Manthorpe & Liffie, 2009):

1.	How the interactions between gender, sexuality, ethnicity, beliefs system and lived experiences influence the experience of dementia in the person
2.	The interrelationship with mental ill health and physical disabilities
3.	The role of the person’s social relationships in shaping and supporting wellbeing
4.	The person’s socio-economic status and how factors like housing might impact on them
5.	The effects of migration, written and spoken languages on dementia
6.	The person’s view on how accessible and approachable professionals are, as well as cultural attitudes to dementia

The Care Act 2014 - In cases where a safeguarding referral for a person living with dementia is made, practitioners must consider their duties under the Care Act 2014. Section 42 of the Care Act requires the Local Authority to consider whether there is reasonable cause to suspect that an adult:

- ❖ Has care and support needs
- ❖ Is experiencing, or is at risk of abuse and neglect **and**
- ❖ As a result of their needs is unable to protect themselves from the abuse or neglect or risk of it

Where these three points are met, then the Local Authority has a statutory duty to make (or cause others to make) “whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult’s case....and if so, what and by whom” (Care Act, Section 42(2)).

Safeguarding decisions must be focused on the 6 principles of the Care Act, which are as follows:

Empowerment	Supporting people to make their own decisions and informed consent
Prevention	It is better to take action before harm occurs
Proportionality	The least intrusive response appropriate to the risk presented
Protection	Support and protection to those in greatest need
Partnership	Local solutions through work with communities
Accountability	Accountability and transparency within safeguarding

Good safeguarding practice should have a broader focus than an assessment of risk; it also needs to consider the context of risk of abuse or neglect and how this relates to a person's care and support needs and their wellbeing. Safeguarding processes should also consider how abuse and neglect may be prevented. This includes the consideration of how existing needs or risks could be reduced, with consideration also being given to future needs or risks. The Care Act statutory guidance states that service may take three possible approaches to prevent need or risks occurring. These three approaches are as follows:

Primary Wellbeing	Prevention/Promoting	Aimed at individuals who are without needs to prevent them occurring (through measures such as promoting safer neighbourhoods or providing information to the community)
Secondary Intervention	Prevention/Early	In which early-interventions may be used to prevent a need or risk arising
Tertiary Interventions	Prevention/Formal	In which formal interventions are provided to reduce a need or identified risk

The Mental Capacity Act 2005 – The five key principles of the Act are as follows:

1.	A person must be assumed to have capacity unless it is established that they lack capacity
2.	A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success
3.	A person is not treated as unable to make a decision merely because they make an unwise decision
4.	An act done, or decision made, for or on behalf of an adult who lacks capacity must be done, or made, in their best interests
5.	Before the act or done, or the decision is made, regard must be had for whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

When deciding what is in the person's best interests, professionals must:

- ❖ Involve the person as much as possible, identifying what their views and wishes are (including what the person would have wanted before they lost the capacity to make the decision)
- ❖ Respect the person's cultural and religious beliefs
- ❖ Talk to people who know the person well – for example: Family or friends or care staff who have a good knowledge of the person
- ❖ Try to limit any restrictions on the person

Supported Decision-Making – Research has shown that people living with dementia want to remain central to decision-making for as long as possible, but can feel that they are excluded from decisions by professionals or family carers (Fetherstonhaugh et al, 2013). The Mental Capacity Act 2005 places a strong onus on professionals to do all they can to give information in the most accessible way, appropriate to that person's needs. The person making the decision needs to be supported in whatever ways possible, to maximise their ability to make decisions.

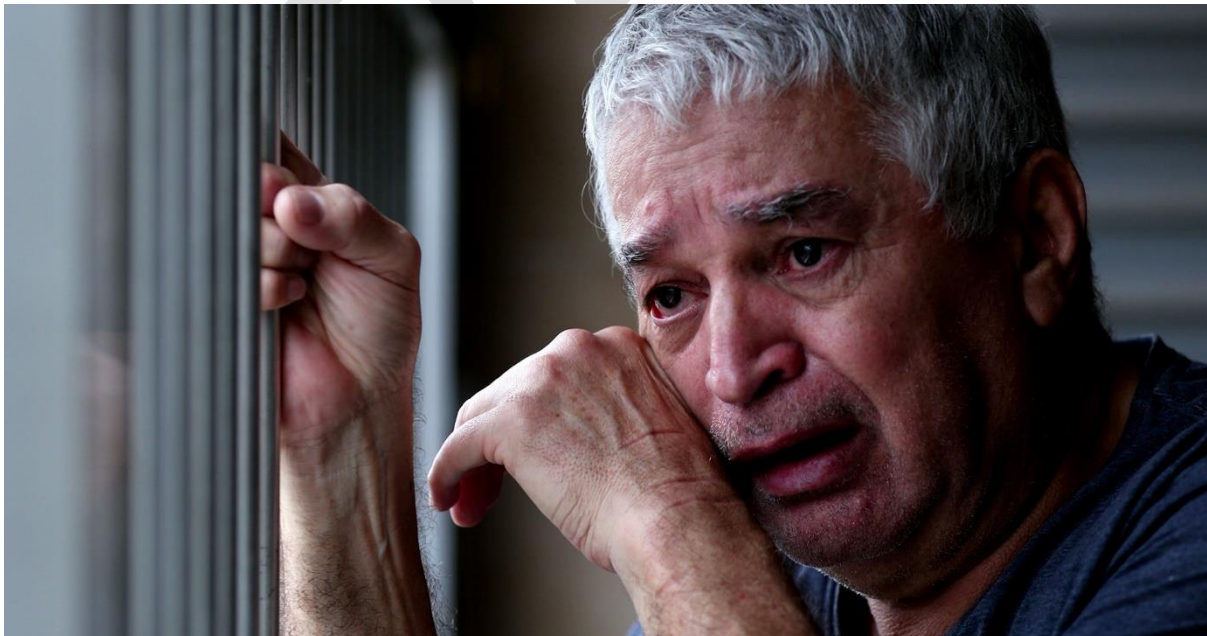
The aim of supported decision-making is to promote autonomy and to prevent the need for substituted decision-making (such as the need to make a best-interests

decision under the Mental Capacity Act) where possible. There are steps that can be taken to aid supported decision-making, such as listening to the person; asking about their preferences and choices in an open non-challenging way; providing the person with clear written information (Davidson et al, 2015).

Advocacy – Advocacy refers to speaking on behalf on oneself or others. Under the Care Act 2014, Local Authorities have duties to involve people in decisions made about them. Where an individual has “substantial difficulty” in being involved in a safeguarding enquiry and does not have an appropriate person to support them, then the Local Authority has a statutory duty to arrange for an independent advocate to be appointed. The Care Act states that a person is experiencing substantial difficulty when they have problems:

- ❖ Understanding relevant information
- ❖ Retaining information
- ❖ Using or weighing information
- ❖ Communicating views, wishes or feelings

An Independent Mental Health Act Advocate (IMHA) may be used in situations in which a person living with dementia has been detained under the Mental Health Act 1983 (in hospital, under Guardianship or on a Community Treatment Order) and where a safeguarding referral has been made. In these cases, an IMHA may also be used to support the person in safeguarding decisions.



5. Good Practice Guidance

It is important to note that people living with dementia are all individuals, whose strengths and needs will vary greatly. Therefore, the following toolkits are not intended to be prescriptive, but more as a means which workers can use to aid their

practice and professional judgement, whilst supporting people living with dementia through the safeguarding process. Below you will find examples of toolkits which have been completed, to help envisage how they can be used in practice. Blank templates of all of the toolkits are attached in the Appendices.

Step 1: Providing people with clear information about safeguarding

Whilst the Care Act came into effect in 2015, many members of the public are unlikely to be aware of it, or what safeguarding means. The Act states that Local Authorities must establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and carers.

Practice Tip: Provide information about safeguarding

Many Local Authorities provide information and posters which set out what abuse is and how people can report it. The information should describe what safeguarding is, the types of abuse and neglect that people might experience and how individuals can report abuse. It should also identify local advocacy services and how people can access them. Halton Safeguarding Adults information can be accessed via the following link: www.halton.gov.uk/adultsafeguarding

Step 2: Think about the person and their environment

When discussing a safeguarding concern with a person living with dementia, it is necessary to consider how best to communicate with the person and where to have safeguarding conversations.

Dementia is an umbrella term for several conditions, as a result of this, people may

experience a wide range of symptoms. These may include memory loss and difficulties with thinking; problem-solving or language. People living with dementia may find it difficult to make safeguarding decisions over the duration of just one meeting. It may need several meetings and information to be written down to ensure the person has had time to consider it fully.

Practice Tip: Thinking about the person's communication needs

It is important to start by assessing the difficulties that an individual experiences and what kinds of help they may find useful. In many cases, the person themselves will be able to say how they find it most useful to receive information. However, information should also be gained from other people who know the person well, such as family carers, social workers or health care professionals.

It is also important to remember that people living with dementia may have other physical disabilities and that these too may have an impact on their ability to understand. People living with dementia will also have

a range of cultural needs or beliefs which may not be immediately obvious to an assessor. Therefore, assessors need to consider an individual's circumstances and should avoid making assumptions.

The following completed example of the template may be used as a checklist to highlight any communication difficulties and cultural needs and any strategies which could be useful (adapted from Carling-Rowland, 2012):

Communication Issues	How Support may be adapted to better suit the person
Type of dementia and its effects on communication	<p>Example Answer: <i>Pauline has vascular dementia. She says that this makes her thoughts slow and that she finds it helpful if people can speak slowly and give her time to absorb each piece of information</i></p>
Method of communication that the person prefers (e.g. verbal information, written information, pictures or graphs (check with the person themselves, family, paid carer or others)	<p>Example Answer: <i>Pauline finds it helpful if workers can write down key pieces of information on a piece of paper when talking to her. This helps her to keep track of the situation</i></p>
Times of the day during which the person is best able to communicate	<p>Example Answer: <i>Pauline says that she has some good and some bad days. However, she normally finds it easier to understand information in the morning</i></p>
Preferred language and whether an interpreter is required	<p>Example Answer: <i>Pauline's native language is English. She does not need an interpreter</i></p>
Any hearing impairments and aids used to address these	<p>Example Answer: <i>None</i></p>
Any visual impairments and aids used to address these	<p>Example Answer: <i>Pauline is short-sighted. Pauline wears glasses to enable her to read the newspapers</i></p>
Communication style or needs	<p>Example Answer: <i>Pauline has a stutter. This is unrelated to her dementia. It tends to get worse at times when she is anxious. Pauline finds it useful if people provide her with plenty of time when she is speaking</i></p>

Cultural Issues	Example Answer: <i>How support may be adapted to better suit the person</i>
Ethnicity	Example Answer: <i>Pauline migrated from the West Indies to England as a child and is a British Citizen. Her older sister remained in the West Indies. Pauline values the opportunity to discuss issues of concern with her sister by phone</i>
Religious views or beliefs	Example Answer: <i>Pauline was brought up as a Christian but now identifies as an atheist. She has stated in the past that she does not have any religious needs and does not wish to be visited by anyone from a religious organisation</i>
Sexuality	Example Answer: <i>Pauline identifies as a lesbian and had a 30-year relationship with Margaret. Her partner died in 2017 and Pauline has not been in a relationship since that time</i>

Practice Tip: Think about what is important to the person

In order that practitioners can promote a person's wellbeing throughout any safeguarding processes, they need to identify what is important to and for the person in question (Sanderson & Lewis, 2011). The following completed example of the one page profile developed by Helen Sanderson Associates, may be used at the outset of a safeguarding enquiry to provide a summary of person-centred information. This tool can help people involved in the safeguarding process, to get to know the person quickly and to provide consistent support for their needs.

Name: (Example Answer)

Pauline Arthur

What people like and admire about me: (Example Answer)

I came to the UK to study nursing and it has always been important to me to help others. I am a friendly person with a good sense of humour. People have always admired my ability to form close relationships with others both in my nursing practice and in the community.

I have always been good at organising things. I set up an after-school club to help working parents in the 1980s and have been a member of the board since I retired. I also set up a choir in my community that ran for 10 years and have made lots of close friends through that.

What's most important to me: (Example Answer)

I see myself as a sociable person, so it is important that I am in regular contact with my family and friends. I am close to my sister in the West Indies, but I can't visit her very easily now. It is important

to me that I get to speak to her regularly by phone or online. I find it useful to ask for her advice at times when I am upset or annoyed. I like to have regular contact with my children and enjoy having visits from them or speaking to them by phone.

I have a wide circle of friends who live in the community. It is important for me to be able to meet them regularly to talk about how things are going and to have lunch. My best friend is David who lives locally. I am also close to Judith and Sarah.

I have always loved music and it cheers me up when I am down. It is important to me to be able to go out and listen to music regularly.

How best to support me: (Example Answer)

Since I have received a diagnosis of dementia, I need to be given time to think decisions through. It helps me if professionals can remind me of who they are and what they are there to do at the beginning of meetings. I also find it helpful if professionals can write down the key points from any meetings on a piece of paper as we are speaking.

It is important for me to have regular contact with my family and friends. I also find it helpful to talk over any important decisions with my sister and with my best friend David.

Practice Tip: Think about where the conversation is held

Safeguarding enquiries involve talking to people about abuse and neglect. This is a sensitive issue and so thought needs to be given about where conversations take place.

People who are living with dementia may become confused when going into new environments for the first time. During the consultation undertaken by the University of Bath, several people living with dementia in the consultation said that they would prefer to be interviewed in a place that they were familiar with, such as at a memory café they attend. A space should be found where a confidential discussion can take place without others over-hearing.

Be mindful of where the alleged abuse or neglect has taken place. Where possible, try and interview the person away from that place. For example, if there is an allegation that a care home resident has experienced abuse in her bedroom, it may be helpful to interview her in another area of the home. It may also be useful to interview the person in a quiet area, so that it is easy for them to focus on and follow the conversation.

The ability of people living with dementia to engage in safeguarding decisions is likely to vary widely. Some people will be fully able to engage in decision-making with little or no support. Others will benefit from having advocates with them or from using decision aids. Some people may have become less practiced at making decisions due to having fewer opportunities in their day to day lives, which may have led to a loss of confidence.

Step 3: Building relationships with the person living with dementia

People living with dementia may find it difficult to communicate with new workers. Where possible, people who are conducting safeguarding enquiries (or who are making an enquiry on behalf of the Local Authority) should work with members of staff who already have an established and trusting relationship with the person concerned. In cases where the person living with dementia is not known to services, then workers should try and build a relationship with the person over more than one sessions, where this is permitted with the level of risk presented.

Drawing on the principles of person-centred dementia care should support this process. Particular attention should be paid to respect, dignity and learning about the person's life story. Activities such as assessments; should be individualised to the needs of the person. Furthermore, workers should be sensitive to the person's religious, spiritual and cultural beliefs and should recognise behaviour which challenges as often this is indicative of an unmet need (NICE/SCIE, 2007). In order to build a relationship, it is important to go at the person's own pace and to make sure they do not feel rushed. This means ensuring that you have the right amount of time with the person to build an effective rapport (Department of Health, 2015).

Practice Tip: Consider Advocacy

Advocacy refers to a process in which an individual is supported by another person to make their wishes known. Professionals should ask people living with dementia whether they would like to have someone with them during a safeguarding meeting and should make efforts to hold the meeting at a time that person can attend. Professionals will of course need to consider whether the person named is connected with the alleged concern, as it may not be appropriate to use them if this is the case. Where individuals do not have people who can support them, professionals should consider making a referral to an advocacy service and should be aware of when the criteria for statutory advocacy services are met.

Step 4: Using Decision-Guides

Conversations about safeguarding can be upsetting and are often complex. It is therefore necessary to think about how people living with dementia might be supported to take part in discussions.

As part of any safeguarding enquiry (whether the allegation is substantiated or not) a person living with dementia may need assistance to identify and weigh up available options. The following completed examples of frameworks (adapted from the Ottawa Personal Decision Guide) can be used to highlight concerns, to map out the options and to identify support which may help an individual to make a capacitated decision.

The Nature of the Allegation

<p>What is the alleged concern? (to be completed by the worker)</p>	<p>Example Answer: <i>Pauline is living in her own house in Runcorn. Her daughter Claire has reported that her brother Andrew has been financially exploiting Pauline. She reports that Andrew has offered to buy Pauline's weekly groceries for her for a small fee. However, Claire reports that Andrew is only buying cheap food for Pauline and is taking at least £30 a week for himself</i></p>
<p>What help or assistance would be helpful to you in talking about the allegation?</p>	<p>Example Answer: <i>Pauline's social worker Chris has been out to see her and has explained the allegation. Pauline says that she would find it helpful if her daughter Claire was involved in any decisions around family. Pauline also sees her best friend David on a weekly basis and would find it helpful to discuss her finances with him.</i> <i>Pauline says that she finds it difficult to remember how much money has been deducted from her bank account each week. She would like help viewing her statements to work out how much money has been debited from her account each week. She would also find it useful for someone to track the shopping that she has received from Andrew and to estimate how much this would have cost</i></p>

Options Available

	<p>Reason to choose this option</p> <p>Benefits / Advantages / Pros</p>	<p>How much it matters to you</p> <p>0 = not at all 5 = a great deal</p>	<p>Reasons to avoid this option</p>	<p>How much it matters to you</p> <p>0 = not at all 5 = a great deal</p>
<p>Option 1. (Example Answer) <i>Continue to allow Andrew to do the shopping and to take payment from my bank account</i></p>	<p><i>I would continue to see Andrew regularly. It would avoid an argument with Rufus</i></p>	<p>4</p>	<p><i>I can't afford to give Andrew as much money as he has been taking. Claire will be angry with me if I continue to give him money</i></p>	

Option 2. (Example Answer) <i>To ask Claire to do my weekly shopping on my behalf and to take money from my bank account as needed</i>	<i>I trust Claire to spend my money wisely</i>	3	<i>Claire is already very busy and lives a long way away. It may cause arguments between Claire and Andrew</i>	5
Option 3. (Example Answer) <i>To ask David to help me order my groceries online</i>	<i>I would be able to choose what food I am getting</i>	5	<i>I don't like packing the groceries away myself</i>	1

Support

	Option 1 Example Answer:	Option 2 Example Answer:	Option 3 Example Answer:
Who else is involved?	<i>Andrew</i>	<i>Claire</i>	<i>David</i>
Which option do they prefer?	<i>Andrew would prefer to keep things as they are</i>	<i>Claire would prefer it if someone else outside the family could help me</i>	<i>David thinks it would be best if I started to do my shopping online with his help</i>
Is the person pressuring you?	<i>Yes</i>	<i>No</i>	<i>No</i>
How can the person support you?	<i>Not Applicable</i>	<i>I would like her to help me work out how much Andrew has been taking from my bank account and how much he has been spending on my shopping</i>	<i>David has offered to help me order my groceries online and to put them in the fridge or cupboards when they arrive.</i>
What role do you prefer in making the choice?	<i>Share the decision with.....</i> <i>Decide myself after hearing the views of</i> <i>Someone else decides</i> <i>Decide for myself after hearing the views of Claire and David</i>		
Which option do you prefer?	<i>Option 3</i>		

Practice Tip: Consider how meetings or discussions are recorded

People living with dementia who took part in the consultation said that they often found it difficult to remember decisions that they had made. People living with dementia identified that in cases where an abuser did not have access to their information, they would like a copy of a safeguarding decision in writing so that they could refer to it later.

Workers might take several steps to help people living with dementia remember the decision:

- ❖ Provide a summary of what was decided at the safeguarding meeting in postcard form
- ❖ Provide a copy of the safeguarding plan as a decision tree so that the person can refer to it
- ❖ Allow meetings to be recorded with the lead professionals giving a summary of what has been decided and any action points at the end of the recording

Practice Tip: Reviewing Practice

The Making Safeguarding Personal approach encourages Safeguarding Adults Boards and individual practitioners to identify what the person central to the safeguarding process wants. It also encourages them to record what the views of that person is, in order that the outcomes from safeguarding work can be reviewed.



Some Safeguarding Adults Board have introduced an “aide memoire” to help review safeguarding outcomes at the end of the process. The aide memoir is completed at the end of the safeguarding process. The aim is to provide a short summary of whether the outcome identified by the person central to the safeguarding process, or their advocates, has been met/partly met/or not met. The aide memoire asks:

- ❖ Have things changed? How have they changed?
- ❖ How do you think that you/we have progressed towards the wishes and outcomes you identified?
- ❖ What helped or prevented the achievement of outcomes?
- ❖ Was there anything that could have been done differently?

The process may also be used to identify the changes that have been made and points which the person may wish to address in the future. However, it may also be used to help the Safeguarding Adults Board to reflect where the needs of people living with dementia are not being met and can influence the future commissioning of services to improve safeguarding outcomes for these people.

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Appendices

Appendix and attachment	no. file	Name	Date of last update
1  Practice Toolkits to support those living		Blank templates of the Practice Toolkits	Sept 2021
2  Guidance_for_people_with_dementia_o		Supporting people living with dementia to be involved in adult safeguarding enquires – Department of Health & Social Care and University of Bath	March 2021