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Supporting people living with dementia to be involved in adult safeguarding enquiries

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Background

This guidance was commissioned by Lyn Romeo in 2019, on behalf of the Office of the Chief Social Worker for Adults. The guidance relates to adult social work practice in England.

The guidance was researched and completed by Dr Jeremy Dixon of the Department of Social and Policy Sciences, University of Bath, Bath.

The practice suggestions in Part 2 of this document are drawn from consultations with people living with dementia, their families and carers, a national co-production advisory group, a care home forum, members of the Principal Social Worker network, as well as other health and social care professionals. We extend our special thanks to all contributors (see acknowledgements).

The following organisations have endorsed this guidance:

- Association of Directors of Adults Social Services
- National Co-production Advisory Group
- Principal Social Workers Network
- Think Local Act Personal



Foreword from the Chief Social Worker for Adults

Research has shown that older adults with dementia are more likely to experience abuse and neglect than those without a diagnosis. People who are living with dementia are entitled to be free from abuse and neglect and where abuse is experienced, and action should be taken to stop and prevent it.

The Care Act 2014 provides Local Authorities with a duty to safeguard adults. However, the needs of people with dementia will vary widely and in order to safeguard people with dementia effectively, practitioners need to be able to adapt their practice.

This year, the Office of the Chief Social Worker worked with Music for Dementia to design [tools to support social workers and link workers](#) to incorporate music into the care plan of people with dementia. We will always endeavour to support interventions like this as they bring immediate impact with tangible outcomes. Practice research and guidance is crucial to this endeavour.

I am delighted to publish this practice guidance which explains what is known about the abuse and neglect of people who are living with dementia and identifies principles for practice as well as principles and suggestions for good practice. The guidance is aimed at social workers however will be of value to all professionals involved in safeguarding adults who are living with dementia.

Fran Leddra

Chief Social Worker for Adults



Introduction

It is estimated that 850,000 people in the UK have dementia, with one 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 and Yan, 2018). Such abuse may include psychological, physical, financial or sexual abuse and can take place anywhere, including the community, care homes or hospitals.

Section 1 of the Care Act 2014 provides Local Authorities with a duty to promote the well-being of individuals. Protection from abuse and neglect forms part of this consideration, although attention also needs to be given to broader concerns. These include the individual's personal dignity, the control by the individual over their day-to-day life and their social and economic wellbeing (see para 1.5 of the Care Act 2014, Care and Support Statutory Guidance).

The Care Act 2014 provides the framework for safeguarding adults in England. It states that the person central to the safeguarding process should be involved in keeping themselves safe and be given choice and control about how they can be supported (Care and Support Statutory Guidance, para 14.11). 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 it to be managed. Because of this, thought needs to be given as to how individuals can be supported to make decisions within enquiries. This guidance focusses on this issue.

This guidance is intended to inform the work of practitioners in England. It is split into two parts. Part 1 provides a summary of the evidence. This focusses on research findings about the abuse and neglect of people living with dementia. It also looks at evidence around how professionals and people living with dementia view the topic of risk. The legal and policy frameworks are then briefly set out, with reference to human rights, the Care Act 2014, the Mental Capacity Act 2005 and Making Safeguarding Personal. Part 2 of the guidance focusses on what might be done to support people living with dementia to be involved in the prevention of abuse and neglect and in finding resolution where it occurs. This section takes the form of 'top-tips'. It is informed by consultation with people living with dementia, family and paid carers, social workers and other health and social care professionals. This guidance has primarily been written to inform the work of social workers undertaking safeguarding work with people living with dementia. However, whilst social services are the lead agency, safeguarding work may be delegated to other health and social care professionals such as nurses, occupational therapists, doctors and domiciliary care workers and this guidance may also inform their practice.

Summary

Research shows that older adults living with dementia are at greater risk of abuse and neglect than those without a diagnosis. Such abuse may include psychological, physical, financial or sexual abuse and may take place in the community or in care homes.

People central to the adult safeguarding process should be involved in the enquiry and be given choice 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 enquiries, in line with the requirements of the Mental Capacity Act 2005.

Research Summary

UK studies focussing on the abuse of people living with dementia have identified high levels of abuse in the community. Most studies rely on self-reports by family or informal carers. They suggest that psychological abuse (verbal aggression or abuse) is the most common form of abuse, with physical abuse and neglect being less common. Studies with Alzheimer's Society employees have identified growing concerns about financial abuse and exploitation in the community, such as people living with dementia been targeted by rogue traders or financial scams.

Several studies have highlighted issues of abuse and neglect of people living with dementia in care homes. Self-reports by care staff have identified several forms of abuse within this setting; most notably threats to residents, avoiding residents with challenging behaviours, not providing enough time when supporting residents to eat and not taking enough care when helping residents to move.

Findings from UK studies have examined the links between the characteristics of the person living with dementia and the levels of abuse experienced. Higher levels of abuse were found in cases where the person living with dementia was perceived by carers to be resistant to care, irritable or displaying challenging behaviours. Higher levels of abuse were also found where family carers had experienced emotional distress, anxiety or depression.

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.

Principles for Practice

The human rights of people living with dementia are protected in UK law through the Human Rights Act 1998 and the Convention on the Rights of Persons with Disabilities. FRIEDA principles can be used as a tool to remember how human rights laws should apply to people living with dementia. These principles focus on Fairness, Respect, Equality, Identity, Dignity and Autonomy.

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 build on these. The approach also involves thinking about how issues of culture and diversity might have an impact on the decision in question.

Knowledge and understanding of relevant legislation and guidance is important for understanding how people living with dementia may be helped to partake in safeguarding enquiries. This includes knowledge of the Care Act 2014 and the related Care and Support Statutory Guidance, as well as the Mental Capacity Act 2005 and its Code of Practice and the Making Safeguarding Personal approach.

Supported decision-making frameworks can be used to assist people living with dementia to make decisions. Previous research has identified useful ways to assist decision-making. These include listening to the person, asking the person about their preferences and choices in an open and non-challenging way, and providing the person with clear written information. Decision-making aids can be used to help people to structure such decisions.

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 term for several conditions (see DH, 2015 for information about the different types of dementia). 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 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, in 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 with living 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 a meeting. They should also review their practice to ensure that future services might better address the needs of people living with dementia.

Part 1 - Evidence Summary

Research Evidence on the abuse and neglect of people living with dementia

International research shows that older adults living with dementia are at greater risk of abuse and neglect than those without a diagnosis (Fang and Yan, 2018). Such abuse often goes unnoticed, because dementia may affect a person's ability to recognise abuse or to report it (Cooney et al, 2006). The number of studies focussing on the abuse of people living with dementia in the UK is still small. However, it is helpful to be aware of their findings because they help us to understand what types of abuse people living with dementia may experience.

UK studies focussing on the abuse of people with living with dementia have identified high levels of abuse in the community. A study by Cooney et al (2006), interviewed family carers to see whether they had abused the person they were caring for. They found that 51% of carers reported 'chronic verbal aggression', 20% admitted physical abuse and 4% reported neglect. A later study by Cooper et al (2009) found that 52% of family carers reported having engaged in some form of abusive behaviour, with 34% of carers reporting levels of abuse which the researchers regarded as important. The most common form of abuse reported was psychological abuse (shouting at or insulting the person) (33%) with reports of physical abuse being much less common (4%). It is possible that these figures under-estimate the scale of abuse as some carers may be wary of reporting it. A further study by Samsi et al (2014) used a survey with Alzheimer's Society workers to investigate issues around money management. Over 90% of workers reported that they were aware of people living with dementia in their area having experienced financial abuse or exploitation, such as being targeted by rogue traders, being charged excessive amounts for services, experiencing theft from the home or being targeted by financial scammers.

Several studies have highlighted issues of abuse and neglect of people living with dementia in care homes. A small-scale study in London found that 8.3% of paid carers reported threatening residents, 8.3% reported avoiding residents with challenging behaviour and 8.3% reported not giving enough food to residents (Cooper et al, 2013). Deliberate abuse was rare, with some staff drawing on coercive strategies (such as using threats to make resident to accept care) due to a poor understanding of dementia. However, a large-scale study of elder abuse in care homes has highlighted higher rates of abuse. Whilst this study was not specific to people living with dementia its findings are important as estimates suggest that 69% of people in care homes are diagnosed with dementia (Prince et al, 2014). The study found that 51% of staff reported that they had seen or reported elder abuse at least once within the last 3 months, with 25% reporting making a resident wait for care and 25% reporting that residents with challenging

behaviour had been avoided (Cooper et al, 2018). Nineteen percent reported that not enough time was given for supporting people to eat and 11% reported that not enough care was taken in supporting residents who needed help to move.

UK studies have examined the links between the characteristics of the person living with dementia and the levels of abuse experienced. Higher levels of abuse were found where the person living with dementia was perceived by family carers to be resistant to care, irritable or to be displaying challenging behaviours (Compton et al, 1997; Cooper et al, 2006, 2008, 2010). Abuse was also more likely where carers had experienced emotional distress, anxiety or depression (Compton et al, 1997; Cooney and Wrigley, 2006; Cooper et al, 2006, 2010). Carers also experienced mounting pressure due to the changing nature of dementia or due to difficulties finding time for themselves due to their caring responsibilities (Singleton et al, 2017).

What research tells us about how people with living dementia, family carers and professionals think about risk

Government guidance (2007a) defines risk as a negative event which may take place in the future. Assessing risk involves making a judgement about how likely an event is to occur and involves a consideration of the effects that risk may have.

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. Government guidance has indicated that risk-taking should be collaborative and should consider the possible benefits of taking risks, rather than just the disadvantages (DH, 2007a; Manthorpe and Moriaty, 2010). However, the term risk may be understood by people living with dementia, family carers and professionals in different ways. It is therefore useful to consider what the research evidence says in this area.

Research with people living with dementia indicates that they are highly aware of dangers and hazards related to their condition. For example, people living with dementia in a range of studies have talked about dangers related to going out alone, not turning off the hob, financial scams and driving (Benbow and Kingston, 2017; Gilmour et al, 2003; Stevenson et al, 2019). Notions of risk were often linked to safety, with one participant in Stevenson et al's study stating that, "It is really important that you can be independent but safe" (2019, p. 1113). Several studies have found that people living with dementia rarely use the word 'risk' to talk about their experiences (Gilmour et al, 2003; Robinson et al, 2007; Stevenson et al, 2019). However, they were still able to discuss their concerns and wishes, with some taking part in decision-making fully and others making decisions with the assistance of carers (Stevenson et al, 2019).

Studies with family carers of people living with dementia has shown that they are acutely aware of the risks that their relatives may face, with carers being concerned that dementia made the person more vulnerable to risk (Stevenson and Taylor, 2018). Carers have identified worries about a range of potential dangers, including falling, getting lost, road safety, cooking and financial management (Gilmour et al, 2003; Stevenson and Taylor, 2018; Robinson et al, 2007). However, studies have indicated that many carers understood the benefits of enabling the person living with dementia to take appropriate risks and would seek to reduce rather than eliminate risk (Stevenson and Taylor, 2018). In addition, carers in one study were critical of professionals for being over-protective, or risk adverse (Robinson et al, 2007).

Research with professionals has found mixed views in relation to risk and dementia. A study by Robinson et al (2007), focussing on attitudes to 'wandering' and dementia found that staff thought that the autonomy of people living with dementia should be balanced against their risk to self or others. The study, which was conducted before implementation of the Mental Capacity Act 2005, found that professionals used the concept of 'best interests' when working with risk but focussed mainly on the harm that the person living with dementia might cause to themselves or others. Similarly, a study of home care managers found that they sought to balance safety and risk against the individual needs of residents but placed a strong sometimes dominant emphasis on 'keeping people safe' (Evans, 2018). A study by Stevenson and Taylor notes a greater awareness of the importance of positive risk-taking amongst staff with one worker saying,

"I think the focus has been on taking positive risks, whereas before when you did risk assessments it was, 'oh we have to stop this, we have to stop that', but now it's about how do we enable people to do this and keep as safe as possible" (Stevenson and Taylor, 2017, p. 1946).

However, the culture of health and social care organisations was seen to be important and could act to promote positive risk-taking or limit it. Staff in organisations which used strengths-based risk assessment tools were more likely to enable risk taking; whereas staff who worked in organisations with a blame culture were more apprehensive about taking risks.

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). In recent times,

greater attention has been given to how human rights laws and principles should be applied to people living with dementia (BIHR, 2016; Shakespeare et al, 2018; WHO, 2015).

A human-rights based approach should be grounded in the principle of participation. People living with dementia have the right to participate in all decisions which affect their lives, including safeguarding decisions. Supported decision-making should be used to enable people to make capacitated decisions where-ever possible and any interventions should respect the person’s dignity, beliefs, individual circumstances and privacy (WHO, 2015).

The human rights of people living with dementia are protected in UK law through the Human Rights Act 1998 and the Convention on the Rights of Persons with Disabilities. Useful guidance has already been written about how the Human Rights Act 1998 may be applied to those living with dementia (see BIHR, 2016) and discussion about how the CRPD may be best applied is ongoing (Shakespeare et al, 2018). Because human rights laws are complex, it is useful to use human rights principles to identify important points and consider how they might apply. 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

	<ul style="list-style-type: none"> • 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

Table 1: FRIEDA principles taken from Butchard and Kinderman (2019)

Applying a Strengths-Based Approach

Strengths-based approaches are a useful way of supporting the human rights of people who are living with dementia. Strengths-based approaches are attributed to Saleeby (2013) who identified the need for professionals to acknowledge and draw on the resources of the individual, family and community, rather than pathologizing them. Workers using this approach should identify things which the person is already successful at and seek to use these strengths. Furthermore, workers should highlight the capabilities of an individual and assess how far these might be used to help them to achieve self-determined goals.

Several practical resources have been used by Local Authorities to support the strengths of individuals throughout the safeguarding process (see LGA / ADASS, 2018a). For example, the 'signs of safety and wellbeing' practice framework uses strengths-based principles to consider strengths alongside needs, risk and harm (Carr, 2011; Stanley, 2016).

Whilst 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 (covered below).

Considering culture and diversity

When considering an individual's culture and diversity. Manthorpe and Iliffe (2009) identify six things that are helpful for workers to consider. These are:

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.

Following these guidelines, attention should be given to the beliefs and identities of individuals, their physical and emotional needs, their social networks and their cultural needs.

The Care Act 2014

The Care Act 2014 gives Local Authorities a range of duties and responsibilities regarding the care and support of adults.

The Care Act obliges Local Authorities to promote individual well-being. Whilst this duty includes an obligation to protect adults from abuse and neglect, it also encompasses a range of other areas including a duty to consider personal dignity; physical mental health and emotional well-being; social and economic well-being and the person's contribution to society, amongst others. There are six principles to the Care Act 2014. These are:

1. Empowerment
2. Protection
3. Prevention
4. Proportionality
5. Partnership
6. Accountability

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 (1) 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 duty to make (or cause to be made), "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" (section 42(2)). However, it is important to remember that safeguarding is not a linear process and that actions to safeguard a person may happen as part of the section 42(1) process (LGA /

ADASS, 2019). Also, the duty to make enquiries should not be viewed as a prescriptive process and may consist of activity which might inform decision-making, such as a new Care Act assessment, under section 9 of the Care Act 2014 or a care plan (see LGA / ADASS, 2019). It is also possible that a change of direction may take place as new information or insights emerge.

Safeguarding decisions must be focussed on the principles inherent within the Care Act, most notable the duty to promote wellbeing and a flexible approach focussing on what matters to the individual (see LGA / ADASS, 2019 for further guidance). Decisions should be grounded in the six safeguarding principles contained within the statutory guidance. These are:

- 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, therefore needs to have a broader focus than an assessment of risk; it should consider the context of risk of abuse or neglect, how this relates to a person's need for care and support as well as the person's wellbeing (see LGA / ADASS, 2018a; White, 2017).

Safeguarding responses should also consider how abuse or neglect may be prevented. This involves both considering how existing needs or risks may be reduced and thinking about future needs or risks. Although there is no single definition of prevention, the Care Act guidance states that services might take three approaches to prevent need or risks occurring. These are:

- Primary Prevention / Promoting wellbeing – 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 Prevention / Early Intervention – In which early-interventions may be used to prevent a need or risk arising.
- Tertiary prevention / Formal Interventions – in which formal interventions are provided to reduce a need or identified risk.

The statutory guidance to the Care Act also endorses the Making Safeguarding Personal Approach – a programme by the Local Government Association (LGA) and Association of Directors of Adult Social Services (ADASS), that was designed to give those who may need safeguarding support more choice and control (Ogilvie and Williams, 2010). The approach recognised that people experiencing abuse may feel disempowered by the abuse or by safeguarding procedures and suggests a range of approaches through which people might be given information and be supported to make decisions. Following this approach, Local Authorities are now asked to monitor the experiences of people using safeguarding services, focussing on areas including their understanding of the safeguarding concern, the degree that they (or their representative) feel listened to, their happiness with the result and the degree to which they feel safer following the enquiry (LGA / ADASS, 2018b). Local Authorities should also ensure that there is a focus on the outcomes which are most important to the person being safeguarded. These findings should then be used to inform and improve safeguarding support and intervention within a locality. These procedures will be highly relevant to people living with dementia who are likely to have specific needs.

The Mental Capacity Act 2005

The Mental Capacity Act 2005 applies to England and Wales and provides a legal framework which promotes and safeguards decision-making. There are five key principles to the Act. These are:

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 to be 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.

The Mental Capacity Act also provides mechanisms through which people can decide in advance, at the point at which they have mental capacity. First, individuals can take out a Lasting Power of Attorney, which is a legal document stating who they would like to manage their property and finances or health and welfare once they lose capacity to make such decisions. Second, individuals have the power to make an 'advanced decision', which is a legally binding document in which they identify medical treatments which they would wish to refuse should they lose mental capacity.

The Mental Capacity Act also identifies what protections should be offered to people who have been deprived of their liberty. The Mental Capacity (Amendment) Bill has introduced new processes which will replace the Deprivation of Liberty Safeguards. These are commonly referred to as the Liberty of Protection Safeguards and will be relevant to people living with dementia in hospitals or care homes who have been deprived of their liberty.

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). Whilst dementia does have a negative effect on a person's ability to make decisions over time, studies show that professionals and family carers often fail to explore what might be done to support the person to make decisions due to misunderstanding the Mental Capacity Act or due to paternalistic attitudes (Jenkinson and Williamson, 2012; Taylor, 2016).

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 second principle also indicates that "A person is not to be treated as unable to make a decision unless all practicable steps to help him [or her] to do so have been taken without success (section 1(3)). In other words, the person making the decision needs to be supported in whatever ways to maximise their ability to make decisions. The need to provide such support has also been emphasised in evaluations of the Mental Capacity Act (HM Government, 2019).

Supported decision-making frameworks have been used in different countries, including the UK (see DH, 2007b). The process can be understood as a way of supporting people, whose decision-making ability may be impaired, to make decisions (Davidson et al, 2015).

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. Previous research has identified several steps which may be used to help people to make decisions. These include listening to the person, asking the person about their preferences and choices in an open and non-challenging way, and providing the person with clear written information (Davidson et al, 2015). Research has indicated that providing aids which help people to identify and weigh up the consequences of decisions can be useful, and that information should be put across in a clear and accessible way (Shogren et al, 2017).

Advocacy

Advocacy refers to speaking on behalf of oneself or others. There are a range of different models. These include 'self-advocacy', where a person speaks up for themselves; peer-advocacy, where someone with a similar experience works with an individual to support them; and case advocacy, where a professional worker helps a person to put their views across.

People living with dementia may benefit from any of one of these models which may be available from local advocacy services. They may also be eligible for a range of statutory advocacy services (see Dixon et al, 2020).

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 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.

In addition, an Independent Mental Capacity Advocate (IMCA) may be used in cases where an individual lacks capacity in relation to one or more decisions and where safeguarding adults proceedings have been started. An IMCA may be used in these cases whether or not the person has family and friends who might support them (see SCIE, 2009).

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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.

Part 2 – Suggestions for good practice

The second part of this guidance identifies how people living with dementia might be supported to take part in safeguarding decisions. The practice suggestions given are drawn from consultations with people living with dementia, family carers, a national co-production advisory group, a care home forum, members of the Principal Social Work network as well as other health and social care professionals. The focus of the framework is on providing a collaborative approach that includes people living with dementia, their carers and social networks as well as professionals involved. The framework has four steps.

It is important to state at the outset that people living with dementia are individuals whose strengths and needs will vary widely. For this reason, the suggestions and tools provided below are not intended to be prescriptive. Rather, they are intended as a means through which workers can approach the dilemmas which they may face in a systematic way and identify solutions using their professional judgement.

Step 1: Providing people with clear information about safeguarding

Whilst the Care Act came into effect in 2015, many members of the public are likely to be unaware of it, or what safeguarding means. Section 4 (1) of the Care 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. Most people living with dementia and their carers that were spoken to during this consultation had not heard of safeguarding and were not familiar with the Local Authority's responsibilities under the Care Act. For example, one person living with dementia said,

“It would be nice if there was a better means of getting that [information about safeguarding] across. It would be good if we could get information about safeguarding from places like the Dementia Café”.

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. This type of information should be routinely used to highlight the nature of safeguarding to the public. 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.

Good Practice Examples - County Durham Safeguarding Adults Inter-Agency Partnership have produced a range of safeguarding resources aimed at members of the public and professionals. They have produced several posters with short abuse stories, designed to help the public recognise and report abuse. They have also created leaflets. These include a leaflet describing 'do's and don'ts if there are concerns that an adult is at risk of abuse or neglect' and leaflets providing safeguarding information and contacts. They also provide an explanation of the safeguarding process for service users and carers. Doncaster Safeguarding Adults Partnership Board and Cornwall Council have produced a short film called, "If you see something, say something". The film promotes the recognition of different types of abuse; (such as neglect, financial abuse, discrimination, sexual abuse and physical abuse) and explains what people can do to report it.

In addition to producing information, Safeguarding Adults Boards should engage with communities, particularly people who may need safeguarding services either now or in the future. For example, events may be held with people living with dementia or their carers at dementia groups or within existing support services. Several resources have been produced to assist Safeguarding Adults Boards to think creatively about this (see Section 4 of LGA / ADASS, 2017).

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 to best communicate with the person and where to have safeguarding conversations.

Dementia is an umbrella term for several conditions. Because of this people may experience a range of symptoms. These may include memory loss and difficulties with thinking, problem-solving or language. People living with dementia who took part in the consultation said that they would find it difficult to make safeguarding decisions over one session. For example, one woman said,

"I wouldn't be able to understand it [the safeguarding concern] in one day. I would need one session to understand it and would need the person to put the concerns in writing, so that I had time to consider it, with someone returning. It is about understanding how each person likes to work".

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 knows the person well, such as family carers, key workers, 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. Consequently, assessors need to consider an individual's circumstances and should avoid making assumptions. The following graph (adapted from Carling-Rowland, 2012) may be used as a checklist to highlight any communication difficulties and cultural needs and any strategies which could be useful.

Communication Issues	How support may be adapted to better suit the person
Type of dementia and its effects on communication	
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)	
Times of the day during which the person is best able to communicate	
Preferred language and whether an interpreter is required	
Any hearing impairments and aids used to address these	
Any visual impairments and aids used to address these	
Communication style or needs	
Cultural Issues	

Ethnicity	
Religious views or beliefs	
Sexuality	

A completed version of the form might look like this:

Communication Issue	Plans taken to address these
Type of dementia and its effects on communication	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.
Method of communication that the person prefers e.g. verbal information, written information, pictures or graphs (check with family, paid carer or others)	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.
Times of the day during which the person is best able to communicate	Pauline says that she has some good and some bad days. However, she normally finds it easier to understand information in the morning.
Preferred language and whether an interpreter is required	Pauline’s native language is English. She does not need an interpreter.
Any hearing impairments and aids used to address these	None.
Any visual impairments and aids used to address these	Pauline is short-sighted. Pauline wears glasses to enable her to read the newspapers.
Any other communication barriers	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.
Cultural Issues	How support may be adapted to better suit the person
Ethnicity	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.
Religious views or beliefs	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.
Sexuality	Pauline identifies as a lesbian and had a 30-year relationship with her partner Margaret. Her partner died in 2017 and Pauline has not been in a relationship since that time.

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 (see Sanderson and Lewis, 2011). The following one-page profile (Helen Sanderson Associates, 2020) 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
What people like and admire about me

What's most important to me
How best to support me

A completed version of the tool might look like this:

Name Pauline Arthur
What people like and admire about me I came to the UK to study nursing and it has always been important for 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 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 on-line. 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

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. The following recommendations were given in the consultation:

People who are living with dementia may become confused when going into new environments for the first time. 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 that 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 practised 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 and family carers who took part in the consultation identified that 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 session, where this is permitted with the level of risk presented.

Drawing on 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 indicating 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 that they do not feel rushed. This means ensuring that you have the right amount of time with the person to build 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. People living with dementia who took part in the consultation said that they would find it easier to take part in a safeguarding decision if they had someone with them that they knew well. Some people said that they would like to speak for themselves but would find the presence of someone they knew well reassuring. Others said that they would want the person that they brought with them to assist them in helping them to understand what was happening in the meeting and in making 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 at which 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 a general advocacy services 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. People living with dementia and carers who took part in the consultation told us that individuals living with dementia often struggle to process complicated information. Specifically, individuals identified that it can be unhelpful for people living with dementia to be offered too many choices at one time. For example, one person living with dementia said,

“As my dementia has progressed, I find it more and more difficult to choose. For example, I have avoided going to the optician for the last few years because I find it impossible to choose between 40 pairs of glasses. What I need is a decision-tree. Giving me either / or options would be helpful, so I can decide between two things and then maybe consider a third against that”.

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 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

What is the alleged concern? (to be completed by the worker)	
What help or assistance would be helpful to you in talking about the allegation?	

Options Available

	Reason to choose this option	How much it matters to you 0* = not at all	Reasons to avoid this option	How much it matters to you 0* = not at all

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	Benefits / advantages / pros	5* = a great deal		5* = a great deal
Option #1				
Option # 2				
Option # 3				
Which option did you prefer? - Option 1? - Option 2? Option 3?				

Support

	Option 1	Option 2	Option 3
Who else is involved?			
Which option do they prefer?			
Is the person pressuring you?			
How can the person support you			
What role do you prefer in making the choice?	Share the decision with... Decide myself after hearing the views of... Someone else decides...		

A completed version of the support decision guide might look like this:

The Nature of the Allegation

<p>What is the alleged concern? (to be completed by the worker)</p>	<p>Pauline is living in her own house in Bridgford. Her daughter Claire has reported that her brother Rufus has been financially exploiting Pauline. She reports that Rufus has offered to buy Pauline's weekly groceries for her for a small fee. However, Claire reports that Rufus is only buying cheap food for Pauline and is taking at least £30 a week for himself.</p>
<p>What help or assistance would be helpful to you in talking about the allegation?</p>	<p>Pauline's social worker Christopher 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.</p> <p>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 how much the shopping that she has received from Rufus and to estimate how much this would have cost.</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</p> <p>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</p> <p>5* = a great deal</p>
<p>Option #1</p> <p>Continue to allow Rufus to do the shopping and to take payment from</p>	<p>I would continue to see Rufus regularly. It would avoid</p>	<p>4</p>	<p>I can't afford to give Rufus as much money as he has been taking. Claire will be angry</p>	<p>4</p>

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my bank account.	an argument with Rufus.		with me if I continue to give him money.	
Option # 2 To ask Claire to do my weekly shopping on my behalf and to take money from my bank account as needed.	I trust Claire to spend my money wisely.	3	Claire is already very busy and lives a long way away. It may cause arguments between Claire and Rufus.	5
Option # 3 To ask David to help me to order my groceries online.	I would be able to choose what food I am getting.	5	I don't like packing the groceries away myself.	1

Support

	Option 1	Option 2	Option 3
Who else is involved?	Rufus.	Claire.	David.
Which option do they prefer?	Rufus would prefer to keep things as they are.	Claire would prefer it if someone else outside the family could help me.	David thinks it would be best if I started to do my shopping online with his help.
Is the person pressuring you?	Yes.	No.	No.

How can the person support you	Not applicable	I would like her to help me work out how much Rufus has been taking from my bank account and how much he has been spending on my shopping.	David has offered to help me order my groceries online and to put them in the fridge or cupboards when they arrive.
What role do you prefer in making the choice?	Share the decision with... Decide myself after hearing the views of... Someone else decides... Decide for myself after hearing the views of Claire and David.		
Which option do you prefer?	Option 3		

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. Individuals identified several things which they found helpful. For example, one woman said,

“I would like a little postcard that I can put on the fridge with all my other things [telling me what had been decided]. I know it would be safe and sound there”.

Other individuals identified that they recorded meetings with health and social care professionals on an MP3 recorder to enable them to remember important information 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 professional 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 in order that the outcomes from safeguarding work can be reviewed. Solihull Safeguarding Adults Board have introduced an 'aide memoire' to review safeguarding outcomes at the end of the process. The aide memoire is completed at the end of the safeguarding process, for example, at a case conference or at the point of case closure. The aim of the process is to provide a short summary of whether the outcome identified by the person central to the safeguarding process or their advocates have been met, partly met or not met. It 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 been met and can influence the future commissioning of services to improve safeguarding outcomes for this group.

Closing thoughts

This guidance has demonstrated that the abuse and neglect of people living with dementia is a serious issue which requires attention from professionals. Safeguarding responses must be informed by the Care Act 2014, the Mental Capacity Act 2005 and human rights principles. Current law and policies identify the need for practitioners to provide person-centred responses which focus on the views and aspirations of the individual. All conversations and actions around safeguarding concerns should be informed by these principles.

Dementia affects different people in different ways and may include memory loss and difficulties with thinking, problem-solving or language. This guidance has identified the need for professionals to make adaptations for people living with dementia to maximise their opportunities for involvement. The guidance has provided several suggestions for practice informed by people living with dementia, dementia carers and professionals working in both community and care settings.

These include:

- providing people with clear information about safeguarding;
- thinking about the person and their environment;
- building relationships with the person living with dementia and using decision tools.

Professionals are encouraged to consider these suggestions for maximising involvement whilst using professional discretion and drawing on other tools and resources as necessary.

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