Carers and safeguarding: a co-production

This briefing was produced by the LGA and the Association of Directors of Adult Services (ADASS).

Many people, both carers and practitioners as well as policy makers, have contributed to this briefing note. The aim has been to produce a document which is useful, concise and accessible but, most importantly, reflects and respects the lived experience of carers.

At this time of the COVID-19 pandemic, all of the communication has been virtual, but the response has been enthusiastic and generous. It has been evident that the need to highlight the issues facing carers, in ensuring that they and the person they are caring for is safe, is particularly pertinent at this very challenging period.

The steering group initially included Carers UK; Association of Directors of Adult Social Care (ADASS); the Local Government Association's (LGA) Care and Health Improvement Programme (CHIP) and the NHSEI Commitment to Carers Programme. As the drafts moved on we were able to draw on the lived experience of carers and practitioners from across England, through the ADASS Carers Policy Network and the ADASS Safeguarding Network.

In particular, we thank colleagues and carers in Cheshire East Council, Norfolk County Council, Somerset Safeguarding Adults Board, Birmingham Safeguarding Adults Board, West of Berkshire Safeguarding Adults Board and Newcastle City Council for their contributions and insight.

Carers and safeguarding

This briefing is talking about ordinary people – carers and cared for – who find themselves in potentially extremely difficult situations that they didn't choose, with immense emotional and practical implications for their lives."
Quote from a carer

Across the UK today an estimated 6.6 million people are carers and increasing numbers of us have carer roles to a greater or lesser extent in our personal lives. Recognising that this is an everyday experience for many people is an important reminder that 'carers' are not to be stereotyped. Carers are from a diverse range of backgrounds. Carers may be parents, daughters, sons, partners, neighbours and friends. Carers may be adults or children, and at risk themselves.

Carers make a huge contribution to the lives of the people in the UK they support, and to the communities around them. Carers' support has been valued at a staggering £530 million per day during the pandemic, an equivalent of £193 billion a year (**Carers UK 2020 'Unseen and Undervalued**). However, carers need access to practical and emotional support to enable them to provide good and safe care, as well as looking after their own wellbeing.

There are concerns about the increased stress and risks posed for unpaid carers as a result of the COVID-19 pandemic. There has been a significant increase in the numbers of new unpaid carers during the pandemic who have taken up caring roles during the lockdowns. For existing carers, there have had to provide additional care, with reduced day and short breaks services, As a result, many people providing unpaid care have been left exhausted, socially isolated and have seen breakdown of caring arrangements. Additionally, carers have also taken a financial hit, and seen their health and wellbeing decline. Carers UK updated their report on the experience of carers during the pandemic **Caring Behind Close Doors** in October 2020 reported that:

- Four in five unpaid carers (81 per cent) were providing more care than before lockdown.
- More than three quarters (78 per cent) of carers reported that the needs of the person they care for had increased recently.

- Most carers (64 per cent) had not been able to take any breaks at all in the previous six months.

- More than half (58 per cent) of carers had seen their physical health impacted by caring through the pandemic, while 64 per cent said their mental health has worsened.

Carers may be involved in situations where someone is at risk of abuse or neglect, that require a safeguarding response. This briefing aims to identify ways of improving practice and securing desired outcomes in those situations for:

- family/friend/unpaid carers speaking up about abuse or neglect within the community or within different care settings;
- family/friend/unpaid carers who may experience intentional or unintentional harm from the person they are trying to support or from professionals and organisations they are in contact with;
- family/friend/unpaid carers who may unintentionally or intentionally harm or neglect the person they support.

This briefing provides an update of the ADASS Advice note Carers and Safeguarding Adults produced in 2011 for frontline workers and bring it in line with the Care Act 2014. It is intended to be used as a practical tool and does not seek to amend or replace existing statutory guidance that may be in place. The briefing will support the improvement in practice regarding safeguarding adults as well as safeguarding their carers.

This work was supported by Local Government Association (LGA) and Association of Directors of Adult Social Services (ADASS), through the safeguarding work stream of the Adult Social Care Hub (joint LGA and ADASS), Care and Health Improvement Programme (CHIP).

The next section looks at the legal basis on which carers can access support. The following section provides two case studies that can be used in teams or training with front line practitioners, and the final section provides some useful tools and resources for practice. This includes a **seven-minute briefing from Birmingham Safeguarding Adults Board**.

Carers Rights under the Care Act 2014

The Care Act 2014 provides the legal framework for supporting carers of adults with care and support needs. Ahead of the implementation of the Care Act 2014, Dame Philippa Russell, then chair of the Standing Commission on Carers, welcomed the legislation which:

In many respects marks a quiet revolution in our attitudes towards, and expectations of, carers. At last, carers will be given the same recognition, respect and parity of esteem with those they support. Historically, many carers have felt that their roles and their own well-being have been undervalued and under-supported. Now we have a once in a lifetime opportunity to be truly acknowledged and valued as expert partners in care." **Dame Philippa Russell**

Section 10 of the Care Act 2014 gives anyone over the age of 18, who is looking after another adult who is disabled, ill or elderly the right to a carer's assessment. Young carers and parents of disabled children also have the right to an assessment by their local council under the Children and Families Act 2014. These assessments should cover topics such as carers' mental and physical health, their ability and willingness to care, and their relationships with others

Section 9 of the Care Act 2014 clarifies that an assessment of a person's eligibility for care 'must consider all of the adult's care … needs, regardless of any support being provided by a carer…information on the care that [the carer provides]… can be captured during assessment, but it must not influence the eligibility determination.' In addition, Section 20 of the Care Act places a duty on councils to meet carers' needs in line with a national eligibility threshold.

The Care Act 2014 places a duty on local authorities to assess young carers before they turn 18, so that they have the information they need to plan for their future. This is referred to as a transition assessment. The Care Act is mainly for adults in need of care and support, and their adult carers. There are some provisions for the transition of children in need of care and support, parent carers of children in need of care and support and young carers. However, the main provisions for these groups (before transition) are in the Children and Families Act 2014.

Working together with carers to achieve good outcomes

This advice note has been developed in consultation with carers as well as practitioners. A quote from one carer, but a view shared by others, expressed a wish to see included:

An upfront acknowledgement of the professionalism of paid practitioners, and of their desire to get things right and do the best by the people they support and of the difficulties they themselves face in achieving these goals."

There was recognition of the challenges and dilemmas faced by staff who may be working with limited resources and, particularly during the COVID-19 pandemic, service constraints. Carers asked for honesty and clarity about what was available by way of support: 'good information and communication about the reality of support; involving us and allowing flexibility in finding the best solution to support us to continue caring'.

Active efforts as part of a neighbourhood/place/system level prevention approach are often needed to identify 'hidden carers': these are people who have assumed a caring role but may not identify themselves as a 'carer' and are therefore missing out on the opportunity for not only potential support but also their involvement as experts by experience.

'The overall message from carers is that equality, support and recognition are all connected and high on their agenda. They want to be recognised and valued for what they do, to have the information to be able to care well and safely and make the right decisions for them and their family. They want their family to have great services that provide choice and independence. They want their health and wellbeing to be as good as it can be and to have regular breaks from caring. They want to have the opportunity of working for as long as possible, to be protected from poverty and have a decent income and standard of living. Having given so much, it is right that they are supported, too.' (**State of Caring 2021 Report**, Carers UK, November 2021)

Key points in working in together with carers

Make sure you know what support is available for unpaid carers in your area. Councils may do things differently; for example in some areas carer's assessments are completed by a carer organisation. Whoever undertakes the assessment should be able to work with the carer in the following way.

- Do not make assumptions about the 'carer' and their circumstances.
- Ask 'Is there a young carer involved?'
- Provide timely and careful assessments of both the carer and the person they are caring for.
- Understand the relevant legislation and being able to apply this to practice with confidence (Care Act; Mental Capacity Act; Liberty Protection Safeguards/DOLs; Domestic Abuse).
- Apply Making Safeguarding Personal principles.
- Apply 'professional curiosity'.

Timely and careful assessments of both the carer and the cared for person is vital for safeguarding

When decisions are made about a person's care arrangements without a full understanding of family circumstances or support network, assumptions can be made which may compromise their safety. At the point of discharge from hospital, for example, the fact that there are family members in the household or nearby does not necessarily mean that they will be in a position to take on caring responsibilities. Equally, it could be the case that family or friends have taken on a carer's role, but without identifying themselves as a 'carer' and therefore are not accessing the support they have a right to and need.

Assessment of both the carer and the adult they care for must include consideration of the wellbeing of both people. A needs assessment of the adult cared for or a carer's assessment is an important opportunity to explore the persons' circumstances and to consider whether there is information or support which could be offered to prevent abuse or neglect from occurring. This could, for example, be in the form of training for the carer about the condition which the adult they care for has, or to support them to care more safely.

Risk of abuse, either for the carer or the person they are caring for, increases when the carer is isolated and not getting any practical or emotional support from their family, friends, professionals or paid care staff. Abuse between the carer and cared for person may be domestic abuse. The definition of domestic abuse extends to paid and unpaid carers if they are also personally connected, such as a family member.

Abuse of carers

Potential situations where abuse of carers is more likely are where the person supported/cared for:

- has health and care needs that exceed the carer's ability to meet them
- does not consider the needs of the carer or family members
- treats the carer with a lack of respect or courtesy
- rejects help and support from outside, including breaks
- refuses to be left alone by day or by night
- has control over the carer's financial resources, property and living arrangements
- engages in abusive, aggressive or frightening behaviours
- has a history of substance misuse, unusual or offensive behavioursdoes not understand their actions and their impact on the carer
- is angry about their situation and seeks to punish others for it and/or
- has sought help or support but did not meet criteria for this.

These factors listed above may indicate that the carer is at risk of being abused themselves by the person they support and care for. They are signs for someone doing an assessment to consider.

Abuse of the cared for person

When risk increases in relation to carers unintentionally or intentionally harming or neglecting the adult they support, often the carer:

- has unmet or unrecognised needs of their own, including health needs
- are themselves vulnerable
- has little insight or understanding of the vulnerable person's condition or needs
- has unwillingly had to change his or her lifestyl
- are not receiving practical or emotional support from other family members
- are feeling emotionally and socially isolated, undervalued or stigmatised
- has other responsibilities, such as family or work
- has no personal or private space, or life outside the caring environment

- has frequently requested help but problems have not been solved
- are being abused by the vulnerable person and/or
- feels unappreciated by the vulnerable person or exploited by relatives or services.

These factors may indicate that a person being supported and cared for is at risk of abuse from their carer and so are factors for someone doing an assessment to consider.

Case study 1: Making safeguarding personal and professional curiosity

Making safeguarding personal and professional curiosity should be central to practice to support safeguarding both carers and the person they care for.

The following case study is taken from a Safeguarding Adults Review and is shared here as an example for discussion and learning, with some observations on lessons taken from the review and some questions to prompt reflection on your practice:

Bill and Mary

Bill was an 86-year-old man diagnosed with vascular dementia and other co-morbidities. Bill lived with Mary, his wife and main carer. Bill was dependent on Mary to provide support for all activities of daily living. He required the assistance of two people and the use of mobility equipment for all transfers. Because of his cognitive impairment, it was difficult for Bill to communicate his own views and wishes. Bill was dependent on Mary to maintain communication with the different agencies involved in his life.

A package of care was set up by the Council, to support Bill to live at home with Mary. The package of care was for one carer to support Mary and Bill with transfers and a weekly visit to a day centre. Mary was hesitant to accept this support as she felt that they could manage. The professionals involved disagreed. Although Bill was assessed as lacking capacity to make decisions with regard to his needs, there was no formal 'best interest' decision made. Professionals continued to give weight to Mary's views and wishes regarding Bill's support, even though they did not agree that they were in Bill's best interests. Follow up visits from professionals highlighted concerns about how they were coping and there were concerns regarding Mary's memory. Mary cancelled the home care services. Bill's daughter was present at one of the visits and highlighted concerns about Mary's ability to care for Bill and that she was increasingly concerned that decisions in Bill's best interests were not being made, with Mary's wishes were being allowed to take precedence. Opportunities to raise safeguarding concerns were missed and Bill continued to be supported under the care management pathway.

During a six-month period, Bill's health deteriorated, and a safeguarding enquiry began, as the concerns about Mary's ability and decision making to supporting Bill continued to escalate. Home care was reintroduced, despite Mary's reluctance. Bill's attendance at the day centre was sporadic. Bill was admitted to hospital after a home visit from his GP and was diagnosed with pneumonia, sepsis and four pressure sores (including 1 at Grade 4). Concerns had been previously raised with regards to pressure care and visits had been undertaken by District Nurses. Bill passed away two days later. A safeguarding concern was raised but this did not go onto an enquiry, as it was the opinion of a manager that Mary had not intentionally neglected Bill and that Mary had needed an assessment in her own right.

Lessons learned

Making Safeguarding Personal: Approaches to adult safeguarding should be person-led and outcome-focused. The Care Act 2014 emphasises a personalised approach to adult safeguarding that is led by the individual, not by the process. It is vital that the adult feels that they are the focus, and they have control over the process. In this case:

Bill's views and wishes were missing; Making Safeguarding Personal principles were not applied.

Disproportionate weight was given to Mary's views and wishes. Mary's wish to care for Bill, whilst well-meaning, may have had unintended consequences such as his assessed needs not being met.

Professional Curiosity/Challenge: Practitioners need support to understand the competing needs of the cared for person and carer and how these interact when a carer may have needs of their own.

Practitioners did not appear to understand the appropriate intervention to apply when a carer has needs of their own – i.e. carers assessment/assessment of need.

Advocacy: Independent Advocates support people to understand their rights under the Care Act 2014, and to be fully involved in a local authority assessment, care review, care and support planning or safeguarding process.

It would have been appropriate to consider appointing an independent advocate for Bill for both his needs assessment and the open safeguarding enquiry.

Safeguarding process: There was a conflict that was not addressed satisfactorily i.e. Mary was named as the person alleged to have caused harm but was also consulted as Bill's representative as part of the safeguarding enquiry

- Bill's daughter was not informed about open safeguarding concerns, although she may have been suitable to contact to act as his representative.
- There was a lack of effective planning around the safeguarding enquiry. Effective plans come from multiagency working with clear delineation between the roles and tasks of each profession, as part of that plan.
- There was no wider consultation regarding Mental Capacity or Best Interest decisions with Bill's extended family.
- Application of the Mental Capacity Act (MCA) was not consistent. There was no record of a MCA assessment for specific decisions.

The learning from this case for all practitioners is presented here as a series of questions.

Case study 1: Questions for future practice: to consider, discuss with your team and inform training plans

- Are you confident in your practice to effectively challenge family members who you believe may not be making decisions that are in the best interests for the individual you are working with?
- How do you ensure that advocacy is considered and implemented, according to the Care Act requirements in your work?
- Are you clear on how to escalate concerns, if in your professional opinion, risks have not been dealt with adequately?
- Are you confident in the application of the Mental Capacity Act in your practice?
- Are you confident and encouraged to always apply Making Safeguarding Personal principles and professional curiosity in your practice?

Case Study 2: Domestic abuse and safeguarding

The following fictitious case study focusses on issues of domestic abuse and safeguarding and is reproduced here with permission of Birmingham Safeguarding Adults Board. It is based on an amalgamation of several Safeguarding Adults Reviews.

Sylvia and Phil

Sylvia was aged 89 and her son Phil, aged 63, who had lived with her for a number of years to look after her. She owned her own home and had been widowed over 20 years. She had one friend who tried to visit her as often as she could, mostly when her son was out.

Sylvia's health had seriously deteriorated in recent years to the point where she had become highly immobile. Her care needs had become significant, which was badly affecting her mood, and she needed help with washing, dressing, toileting, getting in and out of bed, preparing food and taking medication. However, Sylvia remained very alert and had a good memory and still had a very strong-will. She mostly relied upon her son for her day-to-day care and practitioners rarely saw her without him being present. They had been described as always having a 'tempestuous relationship' but nevertheless as being very fond of each other. Over the last few years, she had also had carers from a private agency coming, which had been arranged after she had experienced a few falls and had stays in hospital.

After a fall at home and a visit from the GP, Sylvia disclosed her son had hit her, following which a safeguarding concern was raised . She later denied these allegations, saying that she wanted her son to get more help as he was worn out. She fell a few more times and further similar disclosures were made with various non-accidental injuries being reported by professionals, and Sylvia then withdrawing allegations.

When asked, Phil said that professionals were confusing his mum, she was getting confused and that he was worried about her and that they should talk to him in the future. On other occasions, he talked about frustrations of looking after her and how demanding she could be. Each time the safeguarding enquiries was closed on the basis that Sylvia had mental capacity and she denied that her son had harmed her. Phil struggled to look after her and requested a carer assessment be carried out with his mother present, and he requested to speak with the social worker on their own, however this did not happen. During a temporary respite visit at a day centre, staff observed that Sylvia could be 'difficult' and stubborn. However, when the time was coming for her to go home, Sylvia got very agitated, pushed tables over and said that the staff were assaulting her, when they clearly weren't.

In her home professionals observed Sylvia speaking very cruelly to her son, goading him, saying that she wished he wasn't alive. She also informed carers that she did not like him to be going out or seeing his friends. She would also demand that he provided personal care instead of the carers who were present and was known to tell him that she could get him into trouble with the law or social care.

Despite the increasing stress in the household, Sylvia and Phil turned down additional help that was offered, on the grounds of cost, as Sylvia would have been self-funding and didn't want to go into care as the house would be sold. Sylvia left all the financial matters to Phil, and he was her sole beneficiary in her will. Lots of professionals had been visiting the home, and it was evident that arguments between the two were getting worse. On one occasion a professional witnessed Phil shouting at Sylvia and handling her roughly after she demanded that he support her rather than the care staff present. This resulted in Phil rough handling Sylvia to move her.

This fictious case, based on Safeguarding Adults Reviews raises some key questions for practitioners to consider.

Case study 2: Questions for practice:

1. What indicators of abuse can you see from what you already know?
2. Is the carer also being abused? Is there bi-directional abuse? Think about gender bias.
3. What decisions need to be made and what do you need to take into account?

4. Assuming you could speak with Sylvia and/or Phil what would you need to think about to do this safely?
5. What barriers might Sylvia or Phil experience in talking with you?
6. Whose help do you think you could/should enlist?
7. Could the carer benefit from some support?
8. Are Sylvia and Phil right in thinking they would lose their home?

Useful resources for safeguarding work with carers

- **Seven minute briefing: learning from domestic abuse**: a short briefing produced by Birmingham Safeguarding Adults Board.

- A Carers Safeguarding Risk Assessment tool, **COVID-19, social isolation and safeguarding adults**, was developed and use in by Newcastle City Council, who say: 'it is optional but feedback from those social workers/social care assessment officers who do use it is that they've found it very helpful'.

- Cheshire East Partner Organisations are working together to highlight the complexities of Caring for a Loved one with Dementia, and the additional pressures this brings. Based on feedback from Carers, together with learning from Safeguarding Enquiries, Cheshire East have established a multi-agency response to equip staff in all settings to recognise Domestic Abuse when it is occurring in the context of Dementia, and to respond in a person centred, outcome focussed way. They have produced a toolkit of resources, titled **Care provider response to domestic abuse and supporting people living with dementia and their carers**. For more information please email **joanne.cliffe@cheshireeast.gov.uk**

- Many Safeguarding Adults Boards have dedicated carers and safeguarding pages on their websites, for example, **Norfolk Safeguarding Adults Board**.

- Information for Carers is available from local authorities, for example: **West Berkshire's Information for Carers**.

- Carers Campaigns to promote awareness of and identify 'hidden' carers, such as that promoted by East Berkshire CCG and Signal 4 Carers: 'The aim of the campaign is to ensure that people who are carrying out caring responsibilities recognise themselves as carers and get the help available to them. They may not see themselves as being in need of services and many may feel that they are simply carrying out ordinary responsibilities as part of a family.' Messages appear on the back of local buses and on their interior screens, with the strapline, 'I'm her son/daughter, not her carer'. These show a Freephone number. Calls are answered by Signal4Carers and people signposted to the relevant organisation or service who can help.

- NHS England and NHS Improvement's 'Commitment to Carers Programme' are currently (as of December 2021) working with Healthwatch to conduct interviews with carers with recent experience of the person they care for leaving hospital. They have also commissioned nearly 50 Hospital Trust based projects to look at how carers are being involved and the carer voice is being heard in hospital discharge pathways with a view to developing best practice in working with carers. This work will run until the end of March 2022.