Manchester Safeguarding Partnership

Carers Thematic Learning Review

Executive Summary

This report was commissioned and prepared on behalf of the Manchester Safeguarding Partnership

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1.1 Background and relevant context to the review

This thematic learning review was commissioned in Spring 2021 by the Manchester Safeguarding Partnership (MSP), to understand and learn from the events surrounding 4 similar cases where an adult with care and support needs, who was suffering with physical illness, poor mental wellbeing and significant challenges to their mobility and independence, sadly died whilst under the active care of colleagues working across the Manchester health and social care system.

At the end of the first review panel meeting, following initial discussion of the 4 cases, it was agreed that one of the cases was contextually very different from the others, as the adult concerned and their family carer had not been directly known to health, care and housing services since 2014. It was also judged likely that both the adult with care and support needs and the family carer had a learning difficulty or disability. In addition, the first and only safeguarding alert in relation to this family was raised at the time of emergency admission to hospital in August 2019 and the gentleman sadly passed away around 2 weeks later.

The panel agreed that this case should undergo a separate review process and the MSP supported a desk-top review to ensure that the concerns indicated in the case chronology were addressed through discussion with housing and social care colleagues.

None of the adults with care and support needs in the 3 cases that have been considered had a learning disability or a diagnosed cognitive or neurological condition that may have impacted on their decision-making and judgement.

There are two key similarities in the remaining 3 cases, that form the backbone of the enquiry.

a) **In all cases, a family carer was providing significant levels of care and support to an adult family member that shared their home**.

It is important to be clear about the difference between a family carer and a paid carer, such as a home care worker or a residential care worker. Family carers (also referred to as ‘unpaid carers’ or simply ‘carers’) are not paid and are typically defined as people who support a family member or friend who could not manage without their help, due to illness, disability, alcohol or substance misuse, a mental health issue or a long-term condition.

Caring for a family member with significant health and/or social care needs can be an extremely emotionally and physically demanding experience. Whilst many carers do this willingly and without complaint, sometimes over many years, the impact on their own health, wellbeing and capacity or ability to continue caring can go unrecognised, by themselves and others. When the caring role is very intensive, the family carer may only be able to leave their home for essential reasons, such as food shopping or for medical reasons, which can also lead to social isolation.

In new research recently published by Public Health England[i] the consequences of caring on family carers is explored and concludes that ‘caring is a social determinant of health’. This means that unpaid caring is recognised as having a direct impact on individual mental and physical health and wellbeing, in the same way that living in poor housing conditions or having a poor quality/unsafe working environment might impact negatively on health and wellbeing for example. Having a caring role can therefore have both short and long-term consequences for the lives and wellbeing of family carers, and the longer and more intensive the caring role, the more impactful the effect on the carer is likely to be.

Where it was estimated and documented in records, in one of the cases the extent of input by the family carer was considered to be between 35-50 hours of care per week, in another it was in excess of 100 hours - both included waking overnight to provide care. The threshold for being eligible for a Carers Allowance (a national, financially assessed benefit for carers) is caring for at least 35 hours per week – a level of care that is considered to be regular and substantial, hence carers in this position potentially qualifying for additional financial support.

The legal framework that sets out the approach to assessing and supporting adults with care and support needs - the Care Act 2014 – also makes provision for the assessment and support of family carers, via a ‘carers assessment’. This was the first time that carers were formally recognised in law and the associated intent was to create parity of esteem between carers and the adults they provide necessary care for.

Disability Rights UK[ii] points out that a carers assessment *‘…. is a critical intervention in its own right by helping carers to understand their situation and access relevant support when they require it. This process affects… how carers interact with local authorities as a result.’*

It is also important to recognise that the carers assessment is geared towards understanding the impact the caring role has on the family carer’s *wellbeing* and therefore how to support increased wellbeing for the carer *in their own right*. However, this review also seems to suggest that the process of completing a carers assessment in two of the cases, highlighted the true extent and challenges of the care scenario, and in the weeks/months following a package of care was also arranged for the adult with care and support needs.

Lastly, since the time of these 3 cases, a new Pathway called Carers Manchester, has been commissioned by Manchester City Council with improved access to support for family carers, which continues to be provided through the Voluntary, Community and Social Enterprise (VCSE) sector through a collaboration of 18 services called the Carers Manchester Network. These services are open to all family carers regardless of whether they have had a statutory carers assessment. It has been acknowledged during the review process that access to information and advice for family carers would have been more difficult at the time of these 3 cases.

b) **In all cases, the adult requiring care and support also showed a pattern of behaviour that implied self-neglect**. Self-neglect often has an underlying emotional cause, but it appears in different ways, including:

Lack of self-care – this may involve neglecting personal hygiene, nutrition and hydration, or health more generally
Lack of care of the home environment – this may result in unpleasant or dirty home conditions, as well as health and safety and fire risks, and may also involve hoarding
Refusal of services that could help with health, care or other problems – this may include the refusal of care services, treatment, assessments or wider forms of support such as mobility equipment/aids, housing adaptations

In the cases under review, the most prominent issue was a persistent refusal, directly and indirectly, of offers of medical/clinical care, social care and in some instances aids and adaptations that could assist with mobility and safety around the home. This included declining emergency transport to hospital/admission, not allowing entry to health and care professionals who had arranged to visit the home, declining assessment, and not attending routine GP or outpatient appointments designed to manage and monitor long-term health conditions.

In 2 of the cases, it is apparent that there was an abstract mistrust and fear of hospital admission and/or long-term care, coupled with a very strong desire to receive care and support in the family home from a family member. In one of the cases, being financially assessed (in the case of social care) and needing to self-fund or part fund home care was also a barrier.

Although this refusal of support was typically initiated directly by the adult needing support, there are indications of the family carer appearing to ‘go along’ with the wishes of their loved one. It has not been possible to fully understand in the course of this review whether the family carers fully agreed with these decisions or felt compelled to respect the position of their loved one, perhaps against their better judgement. There is evidence in one of the cases (Colin and Donna) that the carer may have declined the opportunity for regular short-break respite through the sit-in service, because her partner did not want it. The dynamics between the carer and the adult needing support, and the degree to which the carer felt empowered (and was actively empowered by others) to state their own needs and views, remains an important feature of this review.

Lack of self-care, including poor personal care, failing to eat and drink adequately to sustain good health and avoid malnutrition/significant weight loss, and declining to take prescribed medication were also features of self-neglect present in all 3 cases that form this review. Unfortunately, it has not been possible to gain insight from the families' perspectives of what might have been underlying this behaviour and mindset, but the case notes suggest that poor mental wellbeing and low mood were likely to be a factor, potentially alongside lethargy and low levels of motivation to seek help or self-help.

There is no doubt that the day to day lives of the three adults who passed away would have been very challenging and their quality of life severely compromised. Under the circumstances, it is not difficult to appreciate why their levels of motivation and activation may have suffered, after so many years of living with poor physical and mental wellbeing and often significant physical disability.

1.2 The review process

The general aims of this review have been to reach the best understanding of what happened in each case, explore barriers to practice, why they occurred and what could have been done differently. The task of the review panel, led by the independent reviewer, was to explore:

1. When and why barriers to practice occurred and/or why things were not done differently
2. Which aspects of these cases are exceptional or unique, and which aspects are likely to be routinely seen in other cases across Manchester e.g. are they isolated issues or lessons that extend to wider practice
3. Where there is evidence of good practice

4. What remedial action needs to be taken in relation to the findings, to improve awareness and practice

The independent reviewer searched for relevant literature and resources via Social Care Online prior to the commencement of the first review panel. There is a recognised lack of research literature around family caring roles and lived experience and none was found that was directly relevant to the complex cases being reviewed.

The review panel was made up of representatives from all the agencies involved in the 3 cases - from primary and secondary care, including hospital, mental health services and community health services, from Adult Social Care, housing, Greater Manchester Police (GMP), North-West Ambulance Service (NWAS) and from Manchester's Multi-agency Safeguarding Hub (MASH), with co-ordination and planning support provided by the Manchester Safeguarding Partnership business unit. Two advisors to the panel were also invited to take part in the review to provide additional expertise and knowledge. They were a representative of the Carers Manchester network and a Consultant Psychiatrist from Greater Manchester Mental Health Trust (GMMHT).

Supported by case chronologies, a series of appraisals from the agencies involved and additional case notes and records, the review panel met on 3 occasions to scrutinise and discuss the three cases and agree the arising learning points and recommendations. The fourth and final meeting of the panel was a joint meeting with the Adult Practice Review Panel in early October 2021.

To share learning and deepen understanding of barriers to practice, insight was also developed through a Practice Learning Event with a number of colleagues who provided care and support to the 3 families and other practitioners who were working with or had other experiences of the issues seen in the review. One of the most compelling messages to emerge from this session is that working with adults that show self-neglecting behaviour highlights the inherent tension between balancing the choices and wishes of the individual with the duty to safeguard and protect.

The family carers of the adults who sadly died were also invited to provide their views in a way that would be most acceptable to them, but no responses to these invitations were received. In the absence of direct lived experience, to secure a collective carer viewpoint the Carers Manchester network approached its member organisations to ask if carers had any perspectives they would be willing to share. Given that the issues under review are complex and are perhaps not typical of family care scenarios, it was not possible to secure any direct input from family carers. As a next best option, the review panel agreed to convene a discussion between colleagues working in specialist services for carers to assist in exploring some of the central themes from the review. This was proposed and organised by the Carers Manchester panel member and the findings are captured in Appendix A to this report.

This report is the combined product of these activities and deliberations.

1.3 The cases and issues under consideration

Phillip and his family carer Kate

Phillip was 69 at the time of his death in 2019. Self-neglect was visible on admission to hospital, including poor personal care/hygiene and malnutrition. He sadly died the day after admission. Phillip had been a long-term wheelchair user, due to a physical disability linked to an amputation above his left knee. He was diabetic and continued to be monitored for potential complications linked to diabetes, and other health problems, as a hospital outpatient and via his GP surgery. Case notes and medical records also show multiple missed calls, non-response to letters from his GP and repeated non-attendance at health appointments from late 2017 onwards.

Kate his wife appears to have been his primary carer for many years, due to his long-term physical disability. It has not been possible to identify any records that indicate Kate was offered a carers assessment or support for herself as a carer and no carers assessment was found on record. A social care package had been in place during 2017 but the couple chose to cancel this in June 2018 and later declined a referral to Active Case Management in October 2018.

It is difficult to ascertain what happened in the final year of Phillip's life, as there seems to have been relatively limited documented contact with the family.

Colin and his family carer Donna

Colin was a 55 year old man who sadly passed away in 2019. He was found unconscious at his home and was admitted to hospital with severe diabetic complications but unfortunately died 2 days later. Chronic pressure ulcers and personal hygiene issues were noted on admission to hospital.

Colin was an independent man who actively directed and rationalised the care he received. He was registered blind and had undergone the amputation of both legs and was a long-term wheelchair user. He was receiving ongoing care from District Nursing for chronic and severe pressure ulcer sores. His medical records also show many emergency ambulance calls outs and admissions for diabetic complications, suspected/actual heart attack and sepsis, starting from around 2013. Colin was known to have low mood and showed a resistance to care and support, including self-reported wariness of respite or long-term care, and a loss of confidence in health and care staff.

His partner and carer Donna had supported Colin over many years and expressed her frustration to health and care staff in December 2018, stating that the couple were struggling. District Nurses also informally expressed concern about how the couple were coping. Donna had a first carers assessment at the end of January 2019, following involvement of Adult Social Care in early January. It is clear from the carers assessment that Colin is completely dependent on Donna for all his needs and the couple are extremely isolated.

The referral to the Adult MASH Social Work Team in December 2018, prompted by a safeguarding alert, appears to have triggered greater levels of statutory involvement with the family. In the final year of his life, Colin continued to deteriorate and still refused some elements of care. His decline in health was noted and advance care planning was undertaken due to his poor prognosis.

Sue and her family carer Cath

Sue was 26 years old when she sadly passed away. On the day of her death an ambulance had been called to her home, and during the process of moving Sue into the ambulance, she collapsed and went into cardiac arrest.

Sue had multiple physical and mental health issues, her mobility and independence was restricted and she suffered with chronic pain. Sue appears to have been a victim of domestic abuse in her adult life and witnessed domestic violence as a child. For reasons that were not always apparent, Sue repeatedly refused admission to hospital, despite being advised of the risks, and wider efforts to provide care and support were often rejected.

For a period of time Sue was cared for in her mother's home, which was intended as a temporary arrangement. Case notes consistently record that Cath expressed that she was unable to cope with the demands of caring for Sue and her unwillingness to accept care from others. A carer's assessment was completed early in December 2017, which documented that Cath felt isolated and distressed and she was not managing her own physical and mental health conditions well, because of the pressures and time demands of caring.

Sue became consistently known to health services from May 2017, initially due to a leg wound/ulcer and from that point onwards. From late September 2017, she was assessed and accepted onto the mental health care programme approach (CPA), with her care co-ordinated by Greater Manchester Mental Health Trust. Sarah had ongoing support from 9 separate health and care teams, in her home and in the community. From November 2017 until the time of her death, there were multiple ambulance callouts relating to falls and other issues including fever, nausea, and bladder infections. A package of care was put into place shortly before her death.

From the outset, the aim of this learning review has been to understand the circumstances and events in the 12 months before the death of the adult in each case, by considering the care scenario as a whole and paying particular attention to the perspective of the family carers, and their experiences and needs where it was recorded.

This has included an aim to identify:

- the extent of recognition of the family carer and timeliness of support, including their ability and capacity to care for their loved one
- the way in which the presence of self-neglect was recognised and managed by health and care staff
- the challenges of supporting and safeguarding vulnerable adults when they persistently decline support, for both family carers and services.

The matter of quality of life, wellbeing and dignity - in life and at end of life - are significant considerations in this review, for the carer and the adult who sadly died, and are judged to be as important as the extent to which the eventual outcome of premature death may have been avoided.

It is the events within the 12 month timeframe that have been considered in the greatest detail, but other significant knowledge or events which have been important to contextualise the review findings, have been incorporated into the review panel's deliberation. For example, in two of the cases the family carer had clearly been caring for many years by the point of their loved one's death, so the long-term nature of family carer's role was an important factor for the review panel to consider.

It should be acknowledged that the 3 cases reviewed in this process are all highly complex and are likely to have challenged the bounds of knowledge, experience and endurance of the most seasoned health and social care professionals that were involved in working with the families. This complexity includes:

- Each adult experienced multiple physical and mental health and wellbeing issues and symptoms, alongside often significant challenges to mobility and independence
- A level of care and support needs that often demanded intensive levels of input, on the part of the family carer and also health and care colleagues

- Behaviour that suggests self-neglect, particularly persistent refusal of health and care services and support, often explicitly in favour of care at home provided by family members
- The challenges of supporting adults who do not consent to treatment or support and who are judged to have the capacity to make those decisions in an informed way, including understanding that their decision may lead to an immediate or cumulative risk to their life
- Adults and their family carers who could be frustrated and upset on contact with health and social care colleagues, which occasionally tipped over into verbal abuse
- The unknown impact of personal adversity and traumatic life events on the adults and their family carers e.g. acquired disability in adulthood, the effect of seeing or experiencing domestic abuse, fear or mistrust of health and care services based on previous negative or traumatising experiences
- The unknown internal relationship dynamics between the adults and their family carers such as co-dependency, mutual protection, and potentially emotionally controlling behaviour; and factors that may have influenced the family carer’s mindset and decision-making, such as personal and family values and expectations.

The practice notes indicate on several occasions that some health and social care staff were aware of the limits of their training and experience in relation to these cases and voiced this concern, specifically in relation to Sue. This is considered a positive practice point, as showing an awareness of the boundaries of individual expertise and experience and seeking the advice of more experienced colleagues or those from different health or care disciplines, is ultimately in the best interests of the adult with care and support needs and their carer. However, managers and agencies also need to respond to this issue when it is raised by staff, by offering appropriate support and supervision.

To help guide the review enquiries and ensure that the key issues highlighted across the 3 cases were addressed, the lead reviewer developed a set of nine ‘key lines of enquiry’ which were discussed and amended at the first panel meeting. They were:

1. When and how was the presence of self-neglect explicitly recognised in these cases?
2. When and how was the mental capacity of the cared for individual considered in these cases?
3. When and how were the needs and experiences of the family carer assessed?
4. When and how were family carers signposted into broader community support and advice for carers?
5. When and how was the family carer’s capacity to provide care or make appropriate decisions explicitly considered?
6. When and how was there a holistic view taken of the care scenario, including from a risk perspective?
7. When and how was the case escalated (e.g. due to case complexity and/or the situation being stuck)?
8. How could agencies have collaborated differently in relation to the cases?
9. How can practice in relation to the following safeguarding principles in particular be improved? – Empowerment, Prevention, Protection and Partnership

The lines of enquiry have also helped to shape the findings and recommendations of the review panel.

1.4 Thematic learning points

Key learning points from the review are highlighted below, collated under the 4 safeguarding principles that the review considered. Although they are based on the 3 particularly complex cases under review, the panel felt that these reflect general good practice.

Empowerment

- Actively seek to engage the adult with care and support needs, and their family carer(s), to hear and understand their perspectives
- Explicitly consider using psychologically-informed practice, alongside existing strength-based practice, when supporting adults who show self-neglecting or other complex behaviour
- Show due regard for the carer as an expert in the care of their loved one
- Actively direct family carers to support that will help them to manage their own physical and mental wellbeing
- Support informed but realistic choice and control, especially in cases of self-neglecting behaviour, but balance this carefully with duty of care and safeguarding

Prevention

- All practitioners should take active responsibility for earlier recognition and intervention/support for family carers
- Adopt a more robust and enquiring approach to identifying carer stress, risk of carer breakdown, and reviewing the carer's capacity to provide the level and type of care required
- For adults whose needs are complex e.g. they feature physical and mental health/wellbeing and disability/mobility issues, initiate early and more joined up care co-ordination - with the involvement of the carer

Protection

- Continue to develop greater awareness and support practice judgements in instances where adults with known care and support needs repeatedly do not attend or do not engage with healthcare or social care services i.e. supporting professional and practice judgements to determine at what point non-engagement should become a safeguarding concern

- Adopt more robust management of safeguarding alerts, ensuring that they are reported and investigated
- Share the challenges of complex health and care scenarios within supervision, through agency escalation and with other professionals, and agree co-ordinated action e.g. via multi-disciplinary team meetings (MDTs), the Managing High Risk Together pathway etc
- Show explicit consideration of the carers ability to meet the level of care needed, including their ability to undertake care tasks that involve clinical/medical monitoring – discuss with the carer regularly to gauge the potential for unintentional neglect
- Be aware of the potential for family carers' needs to be overlooked by the person they are caring for, which may sometimes lead to unhealthy emotional control over the family carer which reinforces their isolation

Partnership

- Take a whole family approach
- Adopt truly multi-disciplinary practice, by actively initiating greater levels of discussion/consultation and collaboration with other agencies and practitioners, rather than 'internal' team discussion

1.5 Recommendations

The recommendations from this review are grouped into 3 categories – those relating to family carers, those relating to working with adults with complex care and support needs who self-neglect, and those about discharging duty of care effectively.

In developing them, the review panel has considered which aspects of the learning from the review require explicit action by the Manchester Safeguarding Partnership. The recommendations made here are also specifically designed to advance knowledge and practice in areas that the review has highlighted may be most in need of development at a whole system level.

Family Carers

i. Manchester Safeguarding Partnership should convene a meeting to bring together strategic, commissioning and operational carers leads across agencies, and representatives of the Carers Manchester network or other providers of support to carers, to consider the findings of this review (including the insights from carer experience) and any short, medium or long term responses they consider necessary to strengthen awareness of and support for family carers.

   Responses might include the promotion of existing carer identification and support pathways, review / improvement of particular processes or recommendations for future commissioning of support for carers.

ii. The commissioners of services for carers and Carers Manchester are encouraged to collaborate to review the level, type and effectiveness of support and training available to isolated carers with complex and/or very intensive caring roles

iii. The Carers Manchester network is encouraged to co-produce a ‘self-advocacy’ approach with carers, that empowers carers to speak out about what they need and access their rights

Working with adults with complex care and support needs who self-neglect

iv. Manchester Safeguarding Partnership should initiate discussions with the Programme Lead for ACEs and Trauma Informed Practice (MHCC) and the Programme Manager for Trauma Responsive GM, to explore the use of psychologically informed practice and responses with adults that self-neglect

v. Manchester Safeguarding Partnership, supported by adults safeguarding leads, should consider developing a good supervision practice guide, which sets out for practitioners (and managers / supervisors) how they can expect to be supported when they are actively working with self-neglect.

vi. The Manchester Safeguarding Partnership should consider hosting a practice workshop to enable practitioners to explore how to balance professional judgements about choice and control with protection, in cases of adults with capacity who self-neglect

Duty of Care

vii. Using existing channels of communication, the Manchester Safeguarding Partnership partner agencies should creatively promote and reinforce the role and value of multi-professional meetings to manage complex cases, including the new Multi-Agency Meetings (MAMS), Multi-disciplinary Team meetings (MDTs) and the Managing High Risk Together pathway (MHRT)

This may include, for example, explaining the purpose of and distinction between the different approaches, using video case studies, good practice examples, advice for chairing and recording actions from MDT meetings, and first-hand insights from practitioners from different professional disciplines, including general practice, housing, social care, occupational therapy, physiotherapy, district nursing, mental health etc

viii. The Manchester Safeguarding Partnership should develop a concise infographic or pocket guide, which ‘at a glance’ sets out for practitioners what collaborative and effective safeguarding duty of care looks like in practice.

Appendix A – Insight from carer experience

This appendix captures the insight and learning points from discussions held early in October 2021 with colleagues from the Carers Manchester Network. The services/organisations involved in the discussions provide carer-specific support services, and some participants were also current carers. They were:

- Carers Manchester Contact Point
- Carers Manchester central team
- Connect Support – supporting carers of adults with enduring mental health issues
- Lifted – supporting parent carers of children & adults with special learning needs
- Talbot House – supporting families of people with learning disabilities

The discussion focused on 3 questions and the summary points from the conversations are given beneath.

Caring for a loved one who continually refuses help can be very upsetting and challenging – if family carers find themselves in this scenario, what support do they need from services?

- As a general principle, carers or family members who are supporting an adult who is persistently self-neglecting should be proactively offered support by the services that are in touch with the family – this can be simply by asking the carer what help they need, and doing this routinely e.g. on a monthly basis where the level and frequency of care is very intensive and/or there are signs of carer breakdown and/or deterioration of the adult with care and support needs
- Where adults have the capacity to choose not to receive support from services, professionals need to appreciate that the carer still remains a carer, and probably becomes even more isolated when the adult rejects support from services
- It was recognised that the person with care and support needs can sometimes apply significant pressure on their family carer to exclusively meet their care needs, which can put the carer in a challenging and stressful position. It would help if key workers and professionals had greater levels of insight and awareness

about this, as whilst it is not a widespread problem, it does happen within families which can leave carers feeling very vulnerable and unsupported.

- Connecting carers into peer support, to share and hear the experiences of other carers in similar situations, may also help carers to manage their situation and plan realistically for the future
- One of the most popular services requested by carers is counselling. Knowing about the availability of low-cost local counselling across Manchester and how to refer or self-refer would be useful information for services to hold and share with carers

What is the best way to help family carers 'self-advocate' or speak up to say what they need help with - including saying that they can't or don't want to provide care anymore?

- Statutory services should be aware that some carers are wary about asking for help, in case they are held responsible for the care scenario or the deterioration of their family member, which can be a barrier to help-seeking
- Colleagues acknowledged that in reality, most family carers will always find it very difficult to say that they no longer feel able to provide care for their loved one and will usually seek help in order to manage their caring responsibilities for as long as possible, rather than to step away from caring. Conversations therefore need to be nuanced, carefully managed and should aim to support family carers to come to terms with the fact that their coping strategies may be unrealistic when caring becomes very intensive.
- To have a meaningful conversation about changing care arrangements, carers need clarity and honesty about what their options are from professionals
- Very often carers can feel that they carry an overwhelming level of responsibility, including the responsibility to ask for changes to the care scenario, when they may already be exhausted by their situation. Informal or formal advocacy on behalf of carers, by someone who has a degree of independence / no conflicts of interest, could take some of this pressure off carers. Occasionally, Carers Manchester Network services will provide a degree of advocacy for carers who

are really struggling (with their permission), but this is typically an added value task rather than mainstream provision.

How can services and families work together to support and protect adults who have complex, long-term health and mobility challenges, especially when their wellbeing begins to deteriorate and/or they may show some of the signs of self-neglect?

- Carers who are living with the person they are caring for are probably more likely to notice behavioural changes and signs of self-neglect. There was a view that carers who are supporting an adult with an enduring mental health problem may be more likely to recognise that a change in the way that their loved one is looking after themselves, may be a sign of deteriorating mental health and wellbeing and potential relapse. For carers in different situations, training and support may be needed to spot self-neglect and encourage carers to seek help early.
- Carers who are supporting someone with capacity to make decisions whose self-neglect is putting themselves at significant risk, need to be supported by services to understand where responsibilities for keeping the person safe lie e.g. the adult themselves, the family carer, statutory services or a combination. This is often a grey area and whilst carers might not be held responsible for harm arising from their loved one's self-neglect, carers still live with the weight of that responsibility and a fear that they could be.
- Teams or services who are actively working with families should proactively enable the carer to have a voice and for their perspectives and experiences to be heard. It would be ideal if this was a designated role within a service, delivered by someone who does not have a direct working relationship with the family i.e. a dedicated carer support worker.
- Many carers feel that they need a confidential space to talk freely about their concerns about their loved one, as this can be a way of managing the stresses and strains of caring. Counselling is not always easily accessible to carers, which means that some carers will share their concerns with the health and care workers they have regular contact with. Services need to be careful to distinguish between a carer voicing their concerns and frustrations, from a carer

who is reporting a significant change in the adult’s situation which requires formal intervention – services should always seek clarification if they are unsure.

References

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[i] https://www.gov.uk/government/publications/caring-as-a-social-determinant-of-health-review-of-evidence

[ii] https://www.disabilityrightsuk.org/assessment-process-carers-under-care-act