

Keeping Carers in the loop – A Carers Involvement Strategy

1. Introduction

- 1.1 In May 2014 NHS England published its 'Commitment to Carers'. This reaffirmed the NHS's commitment to recognising, valuing and supporting carers as set out in the previous Carers Strategy – 'Recognised, Valued and Supported: Next Steps for the Carers Strategy' (2010). The 'Commitment to Carers' states:

“Carers are a hugely important asset to the NHS. However, too often carers do not receive the recognition and support that they need and deserve from the NHS. We need to do more to help identify, support and recognise their vital roles. Helping carers to provide better care and to stay well themselves will contribute to better lives for those needing care and more effective use of NHS resources.”

- 1.2 Carers are people that provide unpaid support and care beyond what would normally be expected in the realms of the relationship. Caring might be done from a distance or might involve being there day and night for the person being cared for. A carer could be the person an older neighbour relies on to get their food shopping and help with household chores, or a carer could be the person who assists a partner or friend or older child to get washed and dressed and to eat a meal. Being a carer could involve keeping someone from harm if they are confused; having to ensure there is someone with them if they can't be left alone; the carer planning their life and work to ensure they can be there with the person when needed. For some carers it means giving up paid work if the person needs a lot of care.
- 1.3 Carers UK (2014) say that every year, over two million people become carers and a similar number find their caring role comes to an end. There are around 6.5 million carers in the UK – that's 1 in 8 people. By 2037 it is estimated that nine million people will be carers. The care provided, unpaid, by the nations' carers is worth an estimated £119bn per year. Currently 58% of carers are women, although in later life men aged over 75 are more likely to be carers than women.
- 1.4 million people provide over 50 hours of care per week
 - Almost 178,000 children under 18 have caring responsibilities
 - There are just under 600,000 BME carers in England and Wales.
- 1.4 People providing high levels of care are twice as likely to be permanently sick or disabled. The GP Patient Survey in 2013 highlighted the impact of caring on carer health – whilst 51% of non-carers had a long-standing health condition this rose to 60% of all carers and 70% of carers caring for 50 or more hours a week. The survey also highlighted higher levels of arthritis, high blood pressure, long-term back problems, diabetes, mobility problems, anxiety and depression amongst carers. The majority of carers say that caring has had a negative impact on their mental health, including stress and depression.
- 1.5 Of the 178,000 young carers, the vast majority are providing under 20 hours of care a week, however thousands provide even higher levels of care. This is a wide spectrum which means caring will affect these young people in different ways. For example, there is a big difference between a child helping parents to bathe a disabled brother or sister and being the sole support for a lone parent with a severe mental health condition.

- 1.6 Carers UK's evidence indicates that BME carers are less likely to be receiving practical and financial support with caring and more likely to miss out on accessing support for longer – often as a result of a lack of advice and information and struggling to access culturally appropriate services.
- 1.7 Many people do not see themselves as carers - they are mums and dads, husbands, wives, partners, daughters, sons, brothers, sisters, friends and neighbours. They feel they are simply doing what anyone would, caring unpaid for a loved one or friend, helping them through when they are unable to do things for themselves. The caring could be done from a distance of hundreds of miles for relatives who are no longer able to make decisions and choices for themselves, and so rely on others to act in their best interest. Caring from a distance can place an emotional strain on both the family and those supporting the patient or service user.
“relatives are faced with frustration and guilt at not being able to be there for them in their time of need” (Carer)
- 1.8 The caring could be carried out through necessity or choice, and this will often affect how the carer feels about having this role.
“No one ever asked me if I wanted to provide this care for my husband. I worry that I'm expected to provide nursing care with no qualifications or training” (Carer of person living with M.S.)
- 1.9 The Care Act 2014 came into force from April 2015, with much of the responsibility for enacting it sitting with local authorities. However, with greater integration of health and social care we need to ensure we are working closely with the local authority.
- 1.10 This strategy is a refreshed version of the Trust's 'Carers Involvement Strategy' published in May 2011. The strategy includes a new section – KCHFT's Commitment to Carers, and an updated action plan.
- 1.11 Due regard to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it, has been given throughout the development of our strategy.

2. How many carers are there in Kent and what care do they provide?

- 2.1 There are over 151,000 carers in Kent, which means each district council area has between 8,000 and 13,500 carers. 78% of carers are of working age. There are also several thousand young carers in Kent.
- 2.2 Within our Trust we are likely to have at least 500 staff who are carers. The Employers Forum for Carers has gathered evidence on both the impact caring has on the workforce and on the benefits of employers taking a proactive approach to employees who are carers. The Forum's research findings on the impact of caring on their workforces highlighted how the loss of key and experienced employees results in expensive recruitment and retraining costs as well as a loss of expertise and knowledge. 9 in 10 employers surveyed about the impact of dementia caring on their staff said these caring responsibilities were affecting their workforce - putting pressure on employees, causing physical and mental health problems and leading to declined productivity, as well as the loss of valuable staff members.

- 2.3 Whilst the majority of carers care for relatives, one in ten carers (9%) care for a friend or neighbour. According to Carers UK's State of Caring 2014 survey:
- 93% said they provide practical help such as preparing meals, doing laundry or shopping.
 - 87% provide emotional support, motivation or keeping an eye on someone either in person or by phone.
 - 85% said they arranged or co-ordinated care services or medical appointments.
 - 83% said they manage paperwork or financial matters for the person they care for.
 - 71% of carers provide personal care like help with washing, dressing, eating or using the toilet
 - 57% carers were helping the person they care for with their mobility – getting in and out of bed, moving around or getting out of the house.

3. Consulting Carers

- 3.1 As part of putting our initial strategy together in 2010 we talked to both carers' organisations and individual carers, including carers of those with dementia. We also received responses when the draft strategy was circulated in January 2011. Some common issues emerged:

- Most people do not 'choose' to become a carer – it is a sudden illness or circumstance that means they become a carer
- Many carers themselves have health problems, and often have to put these aside in order to provide care

“She was discharged when it was abundantly clear I was unable to cope with her” (Carer with MS who cares for their mother)

- There is a lack of emergency support for patients / service users when their unpaid carer falls ill and is unable to continue caring
- Healthcare organisations assume that spouses and partners are able to perform care tasks, and rarely assess the health or abilities of the spouse or partner when making this assumption. This can lead to complications if the carer has a long-term condition or develops dementia
- When the patient is receiving end of life care, carers are rarely signposted to sources of support in the voluntary and community sector, particularly after the patient has died (e.g. bereavement support)
- Healthcare professionals are unaware of Carers Support or other carer organisations and so rarely sign-post carers to sources of support
- Carers are often isolated and unable to get involved in the wider community and the way healthcare is provided can add to this isolation
- Most carers want what's best for the person they care for – but their knowledge of the person and the person's needs are often not taken into account

“I would certainly appreciate greater recognition of my position as sole carer. It can be so difficult getting myself heard” (Carer of a person with dementia)

- Carers of a same sex partner can find they come into conflict with the relatives of the person they care for when there are difficult decisions to be made at end of life or when the person lacks capacity. Healthcare staff are 'caught in the middle'
- Carers often feel they are not communicated with by healthcare professionals who 'hide behind' data protection and patient confidentiality
- When decisions are made about a patient's discharge from hospital back to their home, carers are rarely consulted or involved in this decision
- Carers Support should be able to in-reach to hospitals to support carers and staff, but there is rarely funding for this. Where such services have been set up there is a benefit to both carers and the hospital
- Many carers are unaware of their right to request a carer's assessment. There is no equivalent carer's assessment in healthcare
- When patients have day surgery little thought is given to whether they are a carer and if this will affect what they can do for the person they care for, or if they are the 'cared for' will the surgery mean their carer will need to provide more support
- Carers are as diverse as the people they care for, but they are even less likely to be consulted or involved if they are young carers, carers who are lesbian or gay, carers from a Black or Minority Ethnic community or carers who have a sensory impairment
- Stereotypes can lead to assumptions, such as a belief that all Asian people all live with extended families who can provide care
- Carers that work face further difficulties, particularly if they are providing over 50 hours a week of care. This is because the care will often be provided in evenings, during the night or at weekends
- Employers rarely look at the needs of staff that are carers. Carers may be reluctant to tell their employer about their caring role through fear of discrimination. If carers are not on the agenda employers are not providing a space for issues to be discussed.

"I work full-time. At times it's a very difficult act to juggle emotionally" (Carer of a father who lives some distance away)

"since flexible working was introduced (with regard to caring), it was nothing more than a written dictum that was avoided by management with the excuse that it could not meet service needs." (Carer who was a nurse and retired from the NHS to care for a parent)

3.2 The systems, protocols and procedures put in place by the NHS with good intentions and for good reasons can lead to carers feeling uninformed, excluded, or even distressed:

- Most healthcare services do not officially recognise carers and so no systems are in place to inform and involve them
- The lack of systems puts carers into conflict with healthcare professionals on a regular basis – causing mutual stress
- Carers are not always the person's next of kin – which can cause conflict when healthcare organisations look to the next of kin for information or decisions
- The Mental Capacity Act can put the professional in conflict with the carer if there are disputes about capacity and 'best interest'

3.3 Healthcare organisations are missing an opportunity if they do not involve carers. With the drive to provide personalised care, the NHS must acknowledge the role that a carer plays in the life of the patient or service user. The NHS must also understand that many of our patients are themselves carers. The Trust generally does not collect the experience of carers as part of our patient experience programme.

4. What should carers expect from health services?

4.1 Carers often do not feel valued or recognised as expert and equal partners in care. Evidence from a survey of carers/relatives of patients at one of our community hospitals showed that we do not always get it right when informing and involving carers and relatives. One carer wrote that their involvement would be improved with *“more communication and updating, to be kept informed of progress. We were never offered this we always had to chase it up.”*

4.2 NHS England widely consulted carers when drawing up the ‘Commitment to Carers’. Carers told them what is important to them:
“Recognise me as a carer” (this may not always be as ‘carers’ but simply as parents, children, partners, friends and members of our local communities);
“Information is shared with me and other professionals”;
“Signpost information for me and help link professionals together”;
“Care is flexible and is available when it suits me and the person for whom I care”;
“Recognise that I may need help both in my caring role and in maintaining my own health and well-being”;
“Respect, involve and treat me as an expert in care”; and
“Treat me with dignity and compassion”

5. What should we aim to provide for carers?

5.1 If we are to recognise, value and support carers there are a number of things we need to do. Carers should expect us to:

- Promote wide understanding in our Trust of the role carers play in supporting our patients and service users
- Ensure that those who are carers are recognised as a carer – the earlier the better
- Have an understanding that age, cultural, relationship and religious differences will affect carers’ lives
- Demonstrate an understanding of the impact that caring has on the health of carers
- Recognise that carers have the right to a life of their own alongside their caring role
- Understand that carers may be the same sex partner of the person being cared for
- Not assume that all patients from Black and Minority Ethnic communities have an extended family that will automatically provide care
- Acknowledge that carers are entitled to have a break from caring and this needs to be considered as part of service delivery

- Provide carers with accessible information about both the condition the person they care for has and what services are available for both the person they care for and themselves
- Involve carers in decisions about the care and treatment of the person they care for, including how the person will be cared for at home
- Ensure our services help support people to continue caring where this is what they want to do and in the way they want to do it
- Not assume that carers can continue caring, especially when the dependency of the person they care for increases
- Sign-post carers to sources of support in the community (eg Carers Support)

5.2 'Carers and personalisation: Improving Outcomes' (Department of Health, 2010) states:

"To recognise carers as expert care partners is to value both their role in providing support and the wider knowledge and skills they possess as individuals. Doing so greatly increases the likelihood of more personalised, responsive, and high-quality outcomes for those being supported, and makes carers' valuable and informed contribution available to other carers, service providers and commissioners."

The report goes on to state:

"Too often, carers have experienced a lack of co-ordination between the assessment of need for the person they support and both their own role in meeting that person's needs, and the support they might need in order to maintain that role."

5.3 Personalised care planning should enable us to meet these expectations. But we cannot do this without giving our staff the information, support, time and training needed.

6. How will we deliver this?

6.1 A number of initiatives are taking place or planned during 2015/16:

- We are consulting on KCHFT's 'Commitment to Carers', and will publish this by October 2015 (see appendix 1)
- Carer awareness will be added to the training provided to staff as part of the roll-out of personalised care plans
- Carer awareness will be added to the corporate induction programme as part of the equality and diversity session
- The carers leaflet produced in 2012 will be updated
- Posters and leaflets about carers' organisations will be available at every clinic and community hospital site
- Work with our partner health and social care providers to provide a more joined up approach to meeting carers' needs and involving carers
- Involve carers' organisations on service planning and development groups

7. Challenges

- 7.1 The needs of carers will not always be the same as the needs of our patients / service users – in many cases they will be different. If the outcome desired is the patient lives an independent life of a good quality, we cannot assume that any additional needs outside of nursing or other health care will be met by the patient's family. This may not always be possible or even safe for the patient. Yet, carers say these assumptions are usually made. Conversely where carers have expertise through years of caring we need to recognise and value this – and help them to continue to be part of the support around the patient or service user.
- 7.2 Many carers do not recognise they are carers and are therefore are less likely to ask for their role to be recognised as part of the patient / service user's life and the care plan agreed. We need to reflect this in the language we use when assessing patients / service users. Rather than say 'do you have a carer?' which can sound both patronising and confusing (as this could be interpreted as a paid carer) we need to ask whether there are family members or friends who provide practical or other support and care to the person.
- 7.3 We need to be sensitive to the fact that many adults who get support from younger children (ie young carers) will not disclose this for fear of child protection issues. Whilst we must safeguard children we must also safeguard adults in what can be very complex family arrangements.
- 7.4 If we know through the assessment process that the person has daily living activities that they need help to do, we must ask who provides this support. If the patient says their partner or parent or friend we must establish that this is informal care, and then ensure that we involve and inform the carer as part of the partnership with the patient. Early recognition and involvement has been proven to be best for the patient and carer, and to save the NHS and social care money in the long run.

8. Benefits of our Approach

- 8.1 Involving carers makes economic sense. The benefits of early intervention and prevention will enable us to maximize use of limited resources. Carer involvement in service design and delivery will also help better direct limited resources.
- 8.2 There are benefits to our staff in this approach. By supporting staff to better involve the family and carers of patients and service users we are likely to receive positive feedback and reduce incidents of aggression or violence towards staff. We already have good practice in services, and our approach is not new – but it will foster consistency and improve quality of care across the Trust.

9. Conclusion

- 9.1 When resources are limited and services are undergoing change we need as many allies as possible if we are to continue to deliver high quality care. By recognising carers as 'expert partners' in care we are bringing additional support and expertise. The costs involved to us are small but the potential benefits are significant.
- 9.2 By recognising that we have staff who are carers, and making sure they have the support they need through flexible working, we will retain a trained and competent workforce, and help attract new staff to harder to fill posts. This will enhance our reputation as an employer.

9.3 We will agree an annual action plan and we will involve carers in an on-going way in reviewing our strategy and setting priorities for action.

10. Acknowledgements

Thank you to the carers who gave up their valuable time to talk to us and to Carers Support for their information and advice.

11. References

This strategy has been drawn up with reference to NHS England's 'Commitment to Carers', The Carers Trust and The Queen's Nursing Institute 'Supporting the health and wellbeing of adult carers', Kent County Council's Adult Carers Strategy, and 'Recognised, Valued and Supported: Next Steps for the Carers Strategy' Department of Health November 2010.

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Update July 2019:

The actions related to this strategy are now included in the Communication, Engagement and Patient Experience Strategy.

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Appendix 1

KCHFT – Our Commitment to Carers

We will recognise you as a carer

Even though you may not see yourself as a ‘carer’ but simply as a parent, partner, child, or friend of the person you provide unpaid care for.

We will involve you

Provided that the person you care for agrees, or it is in their best interests, we will share relevant information with you about the person’s healthcare and treatment, and involve you in discussions about their care plan.

We will sign-post you to information and support

We will provide you with information to help you continue to care for the person you care for – if that is your wish. This may include information leaflets and sign-posting, for example to a carers’ organisation or to getting a carers’ assessment.

We will consider your needs

We understand that we need to be flexible and support you to continue to provide the care you do. This means that we must consider the timing of visits, enabling you to be involved as much as you want to be.

We understand that you may need help both in your caring role and in maintaining your own health and well-being.

We will respect, involve and treat you as an expert in care

We understand that you know the person you care for very well – their likes and dislikes, their preferences, their worries and fears. We promise to listen to you in order to provide the best care we can, together, as part of a team.

We will treat you with dignity and compassion

We recognise that carers are as individual as our patients. We will respect your wishes in terms of religion or culture. We won’t make assumptions about your relationship, for example you may be in a same-sex relationship with the person you care for. We understand how being a carer can be stressful and that sometimes you can feel you are the only one that cares. We will value the unpaid care you provide and acknowledge that the person being cared for may be our patient, but to you they are your mum, your friend, your child or your partner. In other words someone you love, whom it’s hard to see in pain, or unwell, or dying.