

IMPROVING HOSPITAL EXPERIENCES for CARERS



A report based on the experience of Derby carers/families of people with memory loss/dementia during hospital stays.

INTRODUCTION

Partners involved with Carers Support across Derby organised a session about the needs of families/informal carers when people they care for with dementia/memory loss are admitted into hospital or visit as out-patients.

The session took place on 1st December 2016 at Haven House Carers Retreat, 31 Charnwood Street, Derby. It was made possible by Southern Derbyshire Clinical Commissioning Group (SDCCG) and City Council funding (Better Care Fund) for training of informal carers. Over 40 people shared their experiences during the session.

The session focused on three main themes:

- Care and Treatment
- Discharge
- Carers Support during the hospital stay

Every participating carer:

- Had an opportunity to feedback in relation to the three themes
- Received input from three different facilitators
- Had access to the same Creative Carers team members who provided continual support and information packs at the end of the sessions.
- Received a new factsheet developed by Creative Carers, in partnership with the hospital leads, (see Appendix 1)
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This report:

- Summarises the main points carers made
- Includes many individual stories told by carers during the sessions
- Details a variety of actions carers requested
- Contains key recommendations

KEY RECOMMENDATIONS

The main recommendations in this report are:

- Carers need to be identified on admission
- People with dementia need to be identified pre-admission, and from then onwards while in hospital, and their individual needs acknowledged and met
- Training for NHS staff on all wards, irrespective of the medical specialism (because people with dementia have other conditions too) to create dementia-friendly environments
- Individual needs should be understood and catered for, having involved the carer in discussions and decisions about best interests
- 'Share and Care' agreements (where the carer states how they want to be involved in the care during the hospital stay) should be in place and widely understood and used
- Carers should be treated as 'equal expert partners' throughout the hospital experience
- There should be recognition by NHS staff that there are key differences between 'relatives' and 'carers'
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GENERAL SUMMARY OF EXPERIENCES

Carers described their experiences when their loved ones with dementia/memory loss were in the hospital environment. Many of the experiences happened recently although some were as far away as two years ago. All names and some details have been changed to protect the anonymity of individuals involved.

POSITIVE EXPERIENCES

Carers were asked to share their personal stories, including positive ones. Carers responded by telling us:

- After using PALS, a second hospital stay was more comfortable than the first
- A consultant who doesn't specialise in treating people with dementia/memory loss dealt with the situation well
- Despite a general context of bad or difficult experiences, some nurses were helpful

- One carer described her experience as 'brilliant'. She said NHS staff were patient. She told us her loved one has been in hospital three times this year and has only ever received a positive service
- Sometimes the cared for had positive hospital experiences in contrast to the experiences of the carer who often felt uninformed and confused
- One carer told us that they were put in contact with Making Space and they then offered a range of support.
- Carers spoke about the usefulness of question and answer sessions specifically around dementia. They spoke about drop-ins at Dovedale where a physiotherapist, Occupational Therapist, Consultant and Pharmacist are present to respond to questions from carers/families/people with dementia

CARERS STORIES

Carers told their many stories about facing a range of difficulties in hospital. Regardless of time passing, the carers are still emotionally affected by their experiences. They have shared them in the hope that something will change for carers and people with dementia/memory loss. Here is a small selection of stories shared by carers during the sessions (all names and some details changed). Most of the stories carers told were about care and treatment.

CARE AND TREATMENT

"I received a phone call from the hospital to say my husband, who has Alzheimers, had been found crawling around the hospital car park. It was 9pm in the evening. He was confused and cold. He had been discharged without me being told. It was a cold winter evening. He'd fallen by the car park and lost the money I had given him to buy a paper, sweets etc.'

"My mother was left in bed for hours. She needed to go to the toilet. She was left so long that she wet the bed. She was already suffering with pressure sores. I found her soaked in sodden bed sheets. I was very angry when I found out what was happening"

"My mother, who has dementia, was admitted for the day to have a biopsy. We were told to arrive early so arrived at 6.30am. The consultant did not arrive until 10.30am. We were then told we were 4th in the list. By this time, my mother was highly confused and distressed because of the wait. I left the hospital while she was being treated and tried to return to her again several times but the staff said I couldn't. I insisted the final time. I found my mother with her clothes dishevelled and she was really distressed. I discovered she had had no food or liquids for 24 hours. I left her on the assumption that her needs would be catered for."

“My mother was in the Medical Assessment Unit (MAU). She was getting very hot because of her illness. It made my mother very anxious. We both asked if she could have a fan in her room.

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The nurse on duty said one was not available. She told me I could not bring one from home because it can spread infections via dust particles. Her need to become cooler went unmet”

‘Recently, just three weeks ago, my mother had an out-patients appointment. She has a number of physical conditions as well as dementia. She had to have an injection but she is scared of needles. The receptionist was unhelpful and disrespectful and the Senior Sister was also disrespectful. Her personal valuables were just left unattended and not locked away. I felt it was unsafe to leave her unattended in their hands. “

‘My husband kept calling out all the time. He was disorientated in a mixed ward. They changed his medication but didn’t tell me. Eventually, he was put in a room by himself. That’s the worse thing you can do to someone with dementia. Isolate them in an unfamiliar room with no familiar surroundings and no one to communicate with. The only contact he had with anyone was when they came to give him food or drink. The result of all this is he became confused and angry. I tried to tell them he’d be better in a room with others. I was struggling to be with him for many hours at a time because it was getting dark and I had to get a bus home. I did tell them that I would have stayed with him, if I was allowed. In the end, I got him discharged myself rather than prolong the agony for him”

“My wife was taken to Derby Hospital because she had an infection. While in hospital she got MSRA (methicillin-resistant Staphylococcus aureus known as ‘superbug’). There was nothing to say anywhere that she also had dementia. The name on the clip board attached to her bed was wrong. I saw nurses trying to feed her. They would try for a few times and then just leave her, thinking she was not hungry. She will eat – it just requires time and effort. The nurses became busy and forgot to go back to her. I made sure that I was the one who fed her twice a day. That way, I felt more relaxed knowing for sure she had had something to eat.”

‘Casey was on a ward following a physical illness (he also has dementia). A care plan was put together. I was not involved in its creation. He stayed in hospital for 4 days. However, he recovered better at home. It was a familiar environment and the hospital was too busy to care for him properly. He found his strength within his own familiar environment. “

‘My mum has been repeatedly admitted over the last few months. The social worker said that she had mental capacity when she carried out the test. However nurses did not agree. The nurses understood what I was going through and supported me’

‘My Mum, who has dementia, fell asleep when we arrived at the hospital very early in the morning. I sat next to her. I wasn’t ignored but someone came in and started doing procedures on my mum. She woke up startled and confused. My mum became upset and had to be calmed down. I was upset about her treatment and had to leave the room. .A slightly different approach may have avoided my mum’s hostile reaction and the situation escalating as it did”

DISCHARGE

“While he was in the hospital the experience was fine. The problem came on discharge. I didn’t get any notice. I was just told to collect my dad at 4pm. I received no support or signposting. I was on my own. This wasn’t a dementia ward. The staff appeared to have no knowledge about dementia.”

“I was anxious she would be discharged before anything was put in place at home. It was only when I wrote to the Senior Sister that the proper procedures were put in place”

“There seemed to be no process in place for discharge. This was only in May 2016”

“I wasn’t kept fully informed about what was happening. I was not involved in the discharge process.”

CARER SUPPORT

“I did not get any of my questions answered. I was not given advice about new medication. They didn’t ask about his needs on discharge. We were so disappointed by the experience”

“My mother was taken to MAU (Medical Assessment Unit). It was very busy. We waited. My mother was supported but I wasn’t. There was no direction as to what was going on. I wasn’t included even though the information I could have shared could have helped their assessment. I didn’t know who to tell my concerns to. Eventually, when it came to discharge, I received the information I needed. I wanted it earlier on. I wanted to feed into the process from the beginning”

CARE AND TREATMENT – WHAT WOULD HELP

Carers made the following suggestions to improve care and treatment for people with dementia:

- Provide information about dementia on all wards – whether it’s a ward where people with dementia are usually admitted to or not
- Visual identification of people with dementia when staying in hospital or at outpatients including: a coloured strip on their name band to highlight their condition; the same colour put on stickers and attached to relevant paperwork and equipment.
- Use a private whiteboard for staff so that they can be aware of specific needs and carers can update the staff team privately
- Dementia, and types of dementia specifically, need to be recognised from admission to discharge
- Training for staff, regardless of the ward or role, to ensure dementia-friendly approaches at all times

- Ambulance staff trained to enter into EMAS (hospital system) essential information such as alerting NHS staff that they are admitting a dementia patient before the patient arrives at the hospital for admission
- New dementia key workers based at the hospital should introduce themselves to Carers and Cared for on admission.
- Ensure carer is asked on admission if there are any medical concerns about loved ones by treating carer as an 'equal expert partner' rather than a 'relative'
- Highlighting when someone is a carer rather than a 'relative' at the admission stage
- Ensure doors on wards are locked to prevent dementia patients leaving and creating a safeguarding issue. This should also be implemented and monitored at visiting times.
- Negotiate with carers whether it's best for their loved ones to have a single room or be in a ward with others - some carers felt that their loved ones needed a separate room whilst others experienced a separate room as being detrimental to the loved one's health
- Re-assessment after diagnosis kept to a minimum and/or the reasons explained clearly to the carer
- Widely introduce a 'share care' agreement- it formally sets out how much involvement the carer is able/willing to have in the care of their loved one
- The availability of reliable and professional interpreters is important in order to serve all members of our community. The fact that some people only speak community languages other than English should be acknowledged and dealt with professionally rather than as a problem. Asking carers or family members to interpret could create safeguarding or confidentiality issues.
- There should be a dementia social worker / key worker on wards 401, 405-406 8am-4pm, 7 days a week. They should undertake: Therapeutic activities, person centred care, dementia awareness, influence staff on ward, 1:1 supervision, and provide feedback. This would lead to less aggression, less confusion, and fewer feelings of loss

DISCHARGE – WHAT WOULD HELP

Carers made the following suggestions to improve discharge:

- A tick-list should be produced which brings all the discharge processes for different departments and staff and links them together - making the system easier for everyone to follow, including carers

- A clear pathway when loved ones are in and out of hospital during the latter stages of the illness – it needs to include time limits, progression and services needed at that specific time.

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- On discharge, the relevant staff member who carers can call upon for help should be made known to them
- The context of the home environment should be highlighted on admission ahead of discharge to make the process easier so that concerns or advantages can be identified well ahead of the person returning home
- The discharge process should be seamless and would be if the relevant information was picked up on admission, this includes the carer, and everyone involved, knowing about the processes from admission to discharge
- Carers should be regularly updated about medical procedures and medication so that they can prepare for discharge and ensure they have everything they need in place
- Some loved ones may have reached a stage where they can't return home – careful and accurate help in finding the right continuing care needed is essential – especially as some homes don't provide nursing help for dementia residents and some have 'hidden' charges – carers should not be left to deal with what feels like a maze without support

CARERS SUPPORT – WHAT WOULD HELP

Carers made the following suggestions to improve the support carers receive in relation to the loved one's hospital stay:

- If staff involved carers as 'equal experts' in the care and treatment of their loved ones, the stay or visit and discharge would run more smoothly – this needs to be enshrined in procedures
- Need to ensure carers are providing care during the stay because they want to and not because no one else is doing it in the way the carer knows it should be done
- Provide information at the right time in the right place to the carer to assist them in their caring role
- A carer handbook on the ward for the carer to look at which contains useful information such as different types of dementia and different types of carers support
- Carers need to be asked if they are carers (as opposed to or as well as 'relatives') as soon as they arrive at the hospital
- Carer need to have new medication explained to them when the time has come for discharge so they can administer it

- Regular up-dates about treatment, care and discharge should be provided to the carer by someone with the right medical knowledge who can answer additional questions
- Staff should not only tell carers their name but explain their role and who carers can talk to about differing needs

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- There should be good sign posting to the relevant organisations right from the beginning of diagnosis, possibly through GP Care Coordinators (based at the GP practices)
- At the point of diagnosis, there should be a guide for carers about local support
- There should be a clear and known system through which carers can ask questions of medical staff about diagnosis, treatment and care and discharge
- Carers should be treated as 'equal expert' partners from the very beginning which means they're involved in key decisions in relation to care and treatment, environments and discharge
- More work within hospitals to identify carers at an early stage
- Health staff should recognise that hospital visits/stays are stressful times for carers and carers have their own wellbeing needs (signposted or referred to Creative Carers/Derbyshire Carers Association/Making Space for support)
- If the CARER is taken to hospital, they need the 'peace of mind' to know that their loved one is safe – either at home or being looked after elsewhere
- Carers would like more information on types of dementia
- Carers can lose friends when caring, particularly for someone with dementia – being able to make new friends via Creative Carers and/or Making Space is important (therefore hospital staff need to know about what is on offer locally and proactively talk to carers about it)

PATTERNS EMERGING OF CHALLENGES

Whether the story was specifically about care and treatment, discharge or carers support, some patterns emerged from the different workshops. These were:

- The importance of recognising a dementia patient from the start including if the person is admitted to wards for other conditions
- Systems in place as the person stays or is moved around the hospital to cater for their specific needs as someone with dementia
- Process of identifying and then fully engaging the carer from beginning to end
- Getting people with dementia through hospital systems quickly without moving them about unnecessarily (adding to feelings of confusion and disorientation)

- Recognition that some activities on wards (e.g. cleaning) may disturb patients with dementia and plan in advance to address this so additional stress is not caused
- Create a clear pathway for the whole patient's journey so there isn't a feeling of confusion

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- 'Share and care' agreement widely understood and used for carers of people with dementia so that a full picture of carer involvement is known and understood from the beginning
- Changes and improvements should aim to ensure both the person with dementia and their carer are treated as a person; both can feel worthless when systems and individuals let them down
- Information should be given early and in an accessible form
- It's important carers know who to approach on the ward and how carers can be involved in discharge planning
- Dementia can be a taboo subject for NHS staff, the person who has it, and those around them leading to some necessary discussions not taking place

SUMMARY

Carers shared common frustrations and concerns during the session.

One carer asked 'will anything change as a result of today?' Carers were cynical but hopeful. The aim of this report is to set out ideas carers had about improvements and the stories of carers, both positive, and where situations have gone wrong, in order to help create change. As a peer support organisation, Creative Carers will work closely with hospital leads, and other partners, to ensure that changes made are communicated to carers we're in contact with.

The hospital leads intend to come back to Haven House in 6 months to report to carers what has changed as a result of their feedback.

KEY RECOMMENDATIONS

The main recommendations in this report are:

- Carers need to be identified on admission
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- Training for NHS staff on all wards, irrespective of the medical specialism (because people with dementia have other conditions too) to create dementia-friendly environments

- Individual needs should be understood and catered for, having involved the carer in discussions and decisions about best interests

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- 'Share and Care' agreements (where the carer states how they want to be involved in the care during the hospital stay) should be in place and widely understood and used
- Carers should be treated as 'equal expert partners' throughout the hospital experience
- There should be recognition by NHS staff that there are key differences between 'relatives' and 'carers'

ACKNOWLEDGEMENTS

This report has been produced with the help and support of the following partners: Royal Derby Hospital dementia lead and Patient and Public experience leads, Alzheimer's Society, Derbyshire Carers Association (DCA) and Making Space. The session held with carers was funded via our contract with Derby City Council and Southern Derbyshire Clinical Commissioning Group (SDCCG) to deliver training. We provided information packs and our partners gave a range of verbal information to help carers with their caring role while loved ones were in hospital, depending on the session questions. All information given during the sessions had the aim of supporting carers with their caring role during a time of change and uncertainty.

APPENDIX ONE



CARERS SUPPORT: WHEN SOMEONE IS NEARING END OF LIFE

FACT SHEET

Knowing that the end of life is getting closer for someone we care about can bring up unexpected emotions in us. For example, carers/relatives can often feel guilt even though that may not seem logical to anyone else.

Carers tell us they feel more at ease when their loved ones have told them their wishes in advance.

Health professionals are getting better at recognising how important it is to talk to patients and carers/relatives about when life is coming towards the end.

The reason why it's important to have conversations with each other is so that we can all make the end as best as it could possibly be for our loved ones.

Sometimes, we're not always told about what's available to help us do this.

Here are some facts you may not know which can help you/your family when a loved one is in hospital and appears to be reaching the end of their lives:-

- Did you know that the Royal Derby Hospital has a carers diary? You can use it to ask questions and raise concerns about the care of your loved one.
- Did you know that any of us, at any time, can write down what we want to happen towards the end of our life and these will be respected as far as possible? (Derbyshire has a form we can fill in called 'My Future Care').
- Did you know there's a flyer telling us what may happen when we come towards the end of life? Many carers find it helpful to know what to expect.
- Did you know hospitals in Derby have a pack to help carers cope practically and emotionally as a loved one is nearing towards the end of life? It includes: a parking and restaurant voucher, a card for open visiting, a map of the hospital and a leaflet on Chaplaincy services. The nursing staff will give it to the family when they feel it's the right time.

If you would like to know more about support for you, the carer/family member, let us at Creative Carers know on 01332-227711 or telephone Derbyshire Carers for information and advice 01332 200002 or Making Space if you want to talk about your loved one's needs if they have dementia or memory problems on 01332 497 640.

You can also go on to this website: <http://derbyshire.eolcare.uk/> and find the flyers/forms referred to in this fact sheet

Thank you

A BIG thank you to all the carers who shared their personal stories

Creative Carers, January 2017

