HOSPITAL COMMUNICATION AND DISCHARGE DURING COVID 19 - CASE STUDY

June 2020

Healthwatch West Sussex contacted this family, having seen their story, to listen and understand in more detail their experience. We were delighted to be told that telling their story has been cleansing for them.

This family's story highlights areas that can cause concern during *normal* times. The pandemic means these issues can now be magnified with the changes in interactions and limitations on hospital visits. When there are negative impacts, outcomes are intensified.

We hope this case study will help our Health and Care System recognise the impact of the changes arising from the pandemic and seek ways to address these to support patients and their families.

Stanley and Barbara's Story

Stanley and Barbara are both in their 90s and enjoy living independently, in a flat in Coastal West Sussex. Stanley has a history of cancer, and both have been very carefully self-isolating from the start of the pandemic.

One evening in April (2020) Stanley fell and hit his head. There was a lot of blood and his wife, Barbara, was very frightened. His eyes were open, and she thought he was dead. When he came to, he had no memory of what had happened. Barbara called 999 and an ambulance took him to hospital.

At 7am the following morning Barbara had a phone call from the hospital saying that Stanley was OK to come home and that could she come and get him? Barbara had just had an eye operation and her vision was still blurry, so she said no. She was told that was OK, as they would arrange a taxi for him. She was anxious as he had no money, but the staff reassured her that the taxi would be paid for and not to worry.

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Some challenges around discharge:

"We've updated that she was asked to go and collect him. Luckily, she said no, but she could just as easily tried to get on the bus and fetch him. The idea that they'd discharge someone over 90 at 7am in the morning? It felt very uncomfortable with him coming home in a taxi and he'd have been less exposed to risk, if our family had been involved in his transport. Using the taxi meant there was no one to help get dad into the flat. He's a big man and was very wobbly, from shock and tiredness but also hadn't eaten (he normally has breakfast by about 6am). There was no follow-up from the GP and we were concerned, as he was obviously confused, and we were not sure it was just a fall, although that's what it was treated as."

A few days later Stanley collapsed on his way to bed and was again taken to hospital in an ambulance and admitted late evening. This time it was clear it was a blackout. Due to the pandemic situation, Barbara was not allowed to go with him and was obviously anxious and upset. Her anxiety increased as she had no information from the hospital the next day. She tried phoning and eventually managed to speak to someone. All they told her was that he was *having tests*. Later in the day, she received a phone call saying that Stanley would be sent home in a taxi. Barbara asked if he was OK and she was told he'd had a pacemaker fitted.

Transport home:

When the taxi arrived, Barbara found that she had to pay for it, and had to return to the flat to find money. The taxi driver said he was unable to help Stanley out of the car and into the flat. Barbara was left having to help him out of the car and in to their flat, when he could hardly walk. In doing so, Barbara hurt her back.

"We're upset that we only found out dad had a pacemaker fitted on his discharge. We'd tried to contact the Ward and find out what was happening to reassure Mum, but it was a struggle. No one was forthcoming with information. He was in hospital less than 24-hours. Apparently, staff had suggested to him he stay overnight but he asked to go home. However, no one checked whether Mum was able to care for him or that she could get him into the house without help.

After struggling to get him into their home, she rang me in tears. She was too distraught even to think of all the hand-washing and stuff we need to do now. The whole discharge felt careless. They did send back some information about dressings, and Dad' still got wounds on his head from the first fall that hasn't been looked after."

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Changes at home:

Despite having a pacemaker fitted, there has been no follow-up from either the GP or the hospital. Stanley gradually got weaker and less mobile and Barbara was not able to cope. She rang the hospital for advice and was told that it was OK if he was sleepy and not to worry. She didn't receive any support.

By the beginning of May, Barbara was really worried about Stanley, as he was drifting in and out of sleep and very weak. She rang for an ambulance and paramedic attended. They assessed him, but decided he was fit enough to stay home.

Communication during hospital stay:

By the evening, Stanley was very agitated, shaking uncontrollably and felt cold to the touch everywhere, except his head which was burning up. Barbara again rang for an ambulance, and this time he was taken to hospital with suspected COVID-19.

Barbara was told he would need to be tested and was very upset and anxious about Stanley, but also for herself. No information was given to Barbara until the following afternoon, when staff called her to let her know he was being moved to another Ward.

The family waited all day, fearing the worst (COVID). Eventually their daughter rang the ward in the evening – they had been expecting a phone call around midday. She was told that he was on antibiotics. She asked if the test results were back and was told *"oh, I think it was negative"*. She was still not given any information about what was wrong with Stanley, or what was being investigated. Another day, Barbara rang the hospital and asked if the doctor could ring her. She was assured that a message would be passed on. But later that afternoon, Barbara rang her daughter very upset. No one had rung her back and she had not eaten or looked after herself whilst waiting, as she had been too worried about missing the call. When she did manage to get hold of the hospital, she was told the doctor had gone.

"Dad was in hospital for several days before we found out he had a urine infection. It's really hard to get information, as no one rings you back and no one volunteers any information. We'd had to phone daily, often several times. Always lovely people answering the phone. If you don't know the right questions to ask (which mum doesn't) you get no answer. Or they'd tell us that he'd had a scan but not why, or what the result was – always just 'fine' or 'had a good night' or 'doing OK', We kept asking them to keep us informed as we were so worried about a repeat of the previous discharge (taxi, no support, no GP follow-up)."

Stanley was in hospital for nearly 2 weeks, and in this time, Barbara only managed to speak to him 3 or 4 times, (the first time after he'd been in hospital for a week). *"He doesn't have a mobile and wouldn't know how to use one even if we'd been able to get one to him. The nurse told Mum that he was missing her, and that made her upset because she couldn't talk to him and reassure him.*

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"The only time anyone has contacted us is to tell us about a ward change or discharge. The physio department has phoned to discuss mobility aids, but we've been unable to find out what his mobility is like. They also suggested a personal alarm, which Mum agreed to, but they didn't tell her it would cost £20 a month. She only found out after it was fitted, and the paperwork arrived. She was upset and panicked at the cost, and has now cancelled it.

"Not being able to contact him was awful. We only found out about emailing inpatients, via PALS, after speaking to Healthwatch. No one on the Ward mentioned this as a way of staying in-touch. I wish we'd known from the start, as it would have made such a difference.

"Having a daily update from Dad's doctor or nurse would have made it a much more positive experience. Instead it's been awful. And that's not to dismiss the care he had in hospital."

Aftermath:

"Dad's character has really changed since the first fall – he's now muddled and very confused and has lost his confidence. It's also taken its toll on Mum. She's lost a lot of weight and is very anxious. We have a real fear of her crashing and burning and with the COVID restrictions we're unable to help in any meaningful way. Whilst Dad was in hospital, we were more worried about her than him. She was isolated at home with no contact, just waiting for phone calls and not feeding herself as she was too worried about missing a phone call. And her anxiety was bad – one day she was on the phone to me for a total of 6 hours because she was so distressed.

"It's such a different world now that we can't visit, and that didn't seem to be taken into account – the hospital response was as if nothing had changed. The communication was dreadful. We still don't know what tests he was having or why, or what any of the results were. Mum's expectations were not being managed and no one in the family was told enough to know his prognosis e.g. we know he's now has a catheter but no idea if it's temporary or permanent or why.

And no one spoke to us about his health at home. We found out that he needed an enema in hospital as he'd become very constipated. At home he has a diet to ensure that doesn't happen. But weren't able to have two-way conversations with the staff and he wouldn't have thought to "bother" them with that information.

It feels like the first two admissions were rushed; that they wanted him in and out as fast as possible because of the COVID situation.

And there was no joined up thinking – everyone we spoke to was lovely, but it was never the same person – all tried to help but a 50% success rate at best.

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> *So many assumptions made re technology, mobiles, Facebook etc. Older people don't have the same access to the system, and nothing is adjusted to accommodate this. And no one questions their "polite" responses of "I'm fine". My parents are in their 90s, to all intents and purposes shielded in the middle of a pandemic but there were no questions asked – no curiosity into what would happen when they went home, or what was happening to the person at home.*
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> *Wonderful medical care but we were never told what was happening apart from admin details, e.g. ward change or discharge. Neither mum or dad's expectations were managed, e.g. they told her he'd be home after lunch, so she prepared an early lunch so that she'd be ready.*
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> Stanley was discharged recently at night. He had been told he was going to be discharged in the morning, and Barbara was told lunchtime. He was finally discharged late afternoon. They were both frustrated, exhausted and anxious by the long wait and lack of communication.

Further Update.

Healthwatch West Sussex had the opportunity to speak to the family again a week after discharge. They were very pleased that Stanley was home, but things had not been plain sailing. Three incidents particularly made things difficult for them:

1. When the care team arrived the first evening to help Stanley get ready for bed, they requested the night bags for his catheter. Barbara did not know what they meant so they explained that Stanley should have been provided with higher capacity bags for night-time use, and that they could not provide them as it was the hospital's responsibility.

   This omission meant that Barbara had to change Stanley's bag during the night, disturbing both of them. It took several days for Barbara to find out how to get the night bags.

2. Stanley and Barbara were not aware that the carers had only been arranged and funded for two weeks. They only found out when the carers asked them if they would still like visits the following week.

   Barbara has now arranged for them to continue visiting and is paying for them privately. She said that it did mean that they could now visit at times that worked better for her and Stanley. Previously, the carers would arrive to dress him mid-morning and then return to get him ready for bed at 5pm. This meant Stanley, who wakes up at 5am, spent the majority of the day in his pyjamas.

   We are aware that this information may have been shared with Stanley whilst in hospital, but this did not get shared with this wife or family.

   Stanley's GP has advised them that they can claim some of the cost of the carers back. However, Stanley and Barbara felt that this would be too confusing and complicated.

3. Stanley's daughter also described to Healthwatch West Sussex the deep upset she felt when Stanley showed her the message that the PALS communication system had shared with him whilst he was in hospital. She had spent a long time composing an email that explained how much they missed him and how sad they were that they could not visit but that they were thinking of him every day which she had sent with a photograph. The message Stanley showed her was a print-out of the photograph with a short annotation on the back. *What if he'd died and that was his last message?* the daughter said to us.

We have also heard of a similar situation for a patient of St Richards Hospital, where the only information the family can obtain form staff was that their mother was *doing well* and we're *looking at a care plan*. As far as they are aware, there is no system to enable them to ask questions or a way to communicate with their mum. They are concerned about how they will be able to manage her discharge from hospital and her care at home, when they are not part of the conversation.

Summary of opportunities identified

- We hear fantastic examples of hospital teams working hard at sustaining communication with patients and their families who are in COVID wards and would like to see this replicated across all Wards.
- Staff can really support families, particularly those who are themselves vulnerable, by making sure they know about initiatives such as emailing, or having update calls at a set time each day.
- The more informed and involved family and friend carers are, the better prepared they can be to support someone returning home after discharge, reducing the likelihood of the need for re-admittance.

  It is particularly important for families to understand who will be paying for what and for how long.
- Unless families understand what the needs of the person being discharged are (because the treatment has been explained) they may say they do not need help as they do not want to be a burden but the reality they find when the discharged person comes home is different and can quickly be overwhelming.
- Supply everyone discharged a single collation of links and information to Primary Care, Community Hub, Community and Voluntary sector, and trusted Information and Advice so that they can access support as and when needed.

  As part of our membership of the West Sussex Consortia we will progress this initiative, in partnership with the NHS and West Sussex County Council.
- To avoid families asking why there were no checks after patients were discharged from hospital, it is even more important that Primary Care Services are fully informed to allow follow up for all discharged vulnerable patients.