

Event Report

Health Matters Event - Supporting Carers in our hospitals during COVID-19 coronavirus

Health Matters - Supporting Carers was a virtual event that took place on Tuesday 20 October 2020 at 6pm-7.30pm via the Cisco Webex online meetings platform. It was jointly hosted by UHBW and the Carers' Support Centre.

Health Matters is UHBW's programme of public information and engagement events and are organised by the Trust's Membership Team. For the first time, this event was held virtually due to the COVID-19 pandemic. The aim of the event was to increase the recognition of carers' needs and carers' support, particularly during the pandemic, to provide information about support available in our hospitals and in the wider community, to hear and share stories from carers themselves, and to seek feedback about how the health system locally could support them better. We also welcomed representatives from BNSSG Clinical Commissioning Group and Healthwatch, which enabled us to widen the focus of the event beyond support for carers in our hospitals to the health system as a whole. Altogether 23 people joined the event: a mixture of carers, Foundation Trust members and governors, and health service professionals.

The event was structured as follows:

- **Introduction from Jo Witherstone, Senior Nurse for Quality at UHBW/Carers' Lead:** Jo explained the Trust's work to support carers including the Carer's Charter: an agreement signed by the Trust to promote a culture that recognises the vital role carers play within our hospitals.
- **Talk from Judy Gowenlock, Training and Development Worker at Carers' Support Centre:** Judy explained her role as part of the Carers' Liaison Team: part of a small team working within the Trust providing support for unpaid carers. She described the work that the team carried out in providing emotional support, advice and information, acting as a bridge between staff and carers, explaining hospital processes and referring carers to other support where needed. She emphasised that while the team was now working remotely due to COVID-19, they were very much still there to support carers and she described the changes in carer support needs and the increased complexity of these during the pandemic. Her talk highlighted the importance of recognising the variety in the carer experience – 3 out of 5 of us will be a carer at some point in our lives, carers can be any age and their circumstances and support needs will vary enormously.
- To highlight the additional pressures on carers since the pandemic, Judy then introduced **three video clips of carers stories** filmed during Carers' Week in June 2020. Their stories illustrated vividly some of the issues that carers faced during lockdown – isolation, exhaustion, deterioration in health both of the carer and the looked-after person, closure of face-to-face services, groups and respite care, difficulty accessing health services, worry about paid carers coming into people's homes, worry about coming into hospital, concerns about treatment being placed on hold, and anxiety about visitor restrictions in care homes (particularly where patients with complex needs were being discharged to care homes for social worker assessment).
- **Group-work discussions in online 'break-out rooms'** - Tony Watkin, UHBW Patient and Public Involvement Lead, facilitated group-work discussions on two key questions: **What's important to you as a carer in our hospitals? What is the one thing the local health system could do to support you better, particularly during the pandemic?** Feedback from these sessions is recorded below.
- **Concluding remarks** - from Sue Milestone (UHBW Public Governor) and Jo Witherstone, following which Judy Gowenlock brought the event to a close with a poem read by Beth Calverley, UHBW Poet-in-Residence.

Feedback from the Break-Out Groups

There were 5 break-out groups, individually facilitated by Sam Radford, Judy Gowenlock, Richard Fox, Tracey Lathrope and Sarah Murch. Each group was given 20 minutes to discuss the two key questions, after which the facilitators were invited to present the highlights from their groups. The main points were as follows.

Question 1: What's important to you as a carer in our hospitals?

- Effective communication
- Being listened to
- Empathy/understanding/respect towards carers
- Staff treating carers as equal partners in the care of patients
- Recognition that carers are the experts in the care needed
- The Carers' Charter being embedded in practice. Staff to 'own' the charter and use it to engage carers
- A non-judgemental approach
- Help to overcome language barriers (both for those for whom English is not a first language, and also in the terminology used)
- Understanding of cultural barriers and cultural awareness in the context of different approaches to caring
- Recognition that family support is important
- Being able to find information easily – so that people don't have to search for it
- Flexibility in appointments and care
- Recognition that some carers have to juggle 'sandwich care' (a parent and a child they care for) and the different pressures that this brings
- Being included in decision-making around discharge
- Staff should be aware that the next of kin or those with Lasting Power of Attorney are not necessarily the carer, who can therefore sometimes be left out of the decision making process
- Difficulties dropping someone off at the hospital – pre-COVID-19 there were chaperones provided for patients while carers parked their cars.
- An understanding that it can be stressful for the carer if the person that they care for does not react well to the hospital environment
- Extended visiting times would be helpful. However, it was good to see that carers were exempt from the COVID-19 visiting restrictions at the Trust's hospitals
- Concern that there could be a stigma attached to the word 'carer' – some people won't use the word as they don't recognise themselves as a carer.

Question 2: What is the one thing that the local health system could do to support you better, particularly during the pandemic?

- Improve cross-system working to ensure a joined up approach, e.g. a young carer registered as such with a GP might find that a hospital is not aware of their caring responsibilities and therefore does not involve them in decisions as they should. The weariness of continually having to explain the same story was commented on.
- Joined-up mental health services
- Effective use of technology – don't assume that people over a certain age would not be able to cope with it. For example, video calls for physiotherapy appointments would be much more effective than telephone calls.

- Be mindful of digital exclusion issues – not everyone will be able to access technology in the same way. Include ways of communicating that are not digital as there is a risk of creating new health inequalities if everything is moved online.
- More consistency from GPs in communication methods during COVID-19 (e.g. some GPs were good at sending text messages and using appropriate social media channels, some were not, and that more thought could have gone into how some flu clinics were planned).
- The increase in online/telephone GP consultations is having the effect that carers are not always involved in the same way (as long as a patient has capacity, the GP will arrange the call with them, while when visiting in person the carer would have accompanied them). Likewise, social services may only speak to the patient and not the carer, which can cause difficulties for example with people with dementia who might insist that everything is fine even when it is not, meaning that no help is arranged.
- There was concern about a lack of consultation about DNAR (Do Not Attempt Resuscitation) orders, particularly for people with learning disabilities and older people with dementia.
- Concern was expressed that national messaging around ‘protect the NHS’ may be putting patients off seeking treatment. It had been found that some people had not accessed health services when they should have - not because they were nervous about infection, but because they were worried about being a ‘burden’ on the NHS during a period of crisis. This highlights a need for reassurance that the health service is definitely still open for business and consistent messaging that people should still access healthcare when they need it.
- Consideration should be given as to how to address increased feelings of isolation among carers – particularly as community care and support services were often withdrawn with no contact and no follow up. Those who are reluctant to ring up and chase appointments are left without support.
- The health service needed to take account of the ripple effect of people not getting treatment for serious conditions such as cancer treatments and cardiac care.

Conclusions

The event achieved its aims to provide information to carers, raise the profile of carer needs, listen to carers’ stories and seek feedback on health service provision.

Common themes from the group discussions included the importance of communication, listening, empathy and respect in our hospitals. Carers should be viewed as equal partners in provision of care and ‘experts by experience’. While some carers do not identify themselves as such (and perhaps ‘those with caring responsibilities’ describes it better), it is nevertheless important to have some means of identifying and recognising them so that they can get the support and advice that they need. UHBW will take these points into account in its work to refresh and embed its Carers’ Charter.

It is also clear from the feedback gathered that the COVID-19 pandemic has not only increased the numbers of unpaid carers but has magnified the scope and complexity of the challenges that they face. While it is accepted that changes to care provision were necessary due to the need to manage the pandemic and keep people safe from infection, it can be seen that some changes have had difficult consequences for carers and the people they care for. It would be beneficial to ensure when reviewing access to services and communication with patients that any solutions include the involvement of carers as a priority. UHBW, the Carers’ Support Centre and others will therefore use the feedback to inform their work to support carers and to ensure that they can still access the services and the support that they need.