



NHS
The Queen Elizabeth
Hospital King's Lynn
NHS Foundation Trust

NHS
Norfolk and Norwich
University Hospitals
NHS Foundation Trust

NHS
James Paget
University Hospitals
NHS Foundation Trust

2021

Norfolk & Waveney Hospitals Carers Conference

Making Caring Visible and Valued

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Introduction

The Norfolk and Waveney Hospitals Carers Conference was hosted during Carers Week 2021 by the acute hospitals as a collaborative event intended to promote the awareness and support of carers. The theme of the national Carers Week was 'Making Caring Visible and Valued' and this is what the conference was planned to support. The event also served to demonstrate the ongoing collaborative working between the acute hospitals in developing better awareness and support for carers within hospitals in Norfolk and Waveney.

Held virtually, via Zoom, the content of the conference topics and content was chosen collaboratively with local carer organisations and carers themselves. The Patient Experience teams from the acute hospitals approached local carers to ask which topics they were interested in hearing updates on; presenters and content were selected according to their feedback.

Carers, organisations that support carers, and healthcare colleagues were invited to attend, to promote sharing of experiences, discussions and the identification of opportunities for learning. Marketing of the conference was targeted at these groups accordingly, with the support of local organisations and the Trusts' communications departments, though the invite was picked up by other professionals outside of healthcare also. Approximately 40-50 attendees were present throughout each conference session; a mixture of carers, carer organisations, and health and social care colleagues attended and contributed.

Acknowledgements

The conference organisers would like to thank the contributors for their presentations and attendance at the event:

Firstly, our thanks go to the carers who shared their personal experiences of healthcare services, to enable us to further our understanding of carers' experiences, and to identify where there are opportunities for improvement. Having this opportunity to listen to you as carers directly was so powerful, and we hope that you feel supported knowing that we are collectively listening to carers' experiences. We welcome you to be involved as we work to improve carers' experiences at our hospitals.

Secondly, our thanks also go to our contributors who presented the ongoing work regionally in support of carers: Sarah Boyd, Jodie Deards and Cath Pickles. We look forward to working with each of you more as we explore how we can utilise digital healthcare, carers passports, and training about marginalised carers, to improve the experiences of carers at our Trusts.

Finally, we would like to thank Belinda Jones and Kerrie Campbell from Caring Together, for delivering a Carer Awareness Training session for our attendees. Raising awareness amongst our colleagues prompts more conversation about how we can better support carers, and we appreciate your ongoing support with delivering regular training opportunities for our hospital colleagues.

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Agenda

The conference agenda was formed of two sessions; a morning session focused on hearing from carers directly – and sharing ongoing work and improvements with carers - and an afternoon session focused on improving awareness of carers for our healthcare colleagues. Whilst each session had a target audience, everyone was welcome to attend either or both sessions, regardless of their carer or healthcare professional status. As with the content of the agenda, the timings of the conference were led by carer feedback on their preferences for having a morning session for carers.



Agenda

10:00 Welcome

10:15 Presentations for Carers

- Carers passports - at admission and discharge
- Digital Inclusion

10:45 Discussion/Feedback

11:00 Carers Voices - Carers share their experiences

11:50 Feedback on the morning session

12:00 - 13:00 Lunch Break

13:00 Carer Awareness Training - for healthcare staff

14:15 Marginalised Carers - Restitute presentation

14:45 Pledge Making and Closing of Conference

Carers and healthcare colleagues are welcome to attend all sessions.

Jodie Deards – Carers Passports

Jodie Deards (Carers and Patient Experience lead for the East of England, NHS England and Improvement) presented the NHS commitment to carers and how a carer's passport is envisaged for the NHS to ensure that carers are visible, valued and involved in the care needs and provision of the person they care for. Jodie put into context the impact of COVID-19 restrictions on carers. The presentation focussed on what 'good' would look like following research undertaken with carers to highlight the changes within all levels of the NHS that could be implemented to improve the lives of unpaid carers. Information, involvement and communication are key to ensuring that patients and carers have the best experience. Jodie invited carer attendees to contribute to this project's development.

Sarah Boyd – Digital Inclusion

Sarah Boyd (Head of Digital Experience & Transformation, Norfolk & Waveney Integrated Care System) presented the plans across the Integrated Care System relating to digital inclusion. Sarah discussed the desire to ensure that patients and carers are not excluded from future developments in health due to digital exclusion, the progress to date and future plans. Conference attendees were invited to contact Sarah to comment or to become further involved to shape the work currently taking place.

Cath Pickles – Restitute – Marginalised Carers

Restitute is an organisation that support the people who care for survivors of sexual or violent crime, often referred to as 'hidden carers' and 'third party victims of crime.'

While many victims of crime prefer to refer to themselves as survivors, the lack of awareness, support and stigmatisation faced by people caring for survivors, means that their needs are often misunderstood, although primary victims are only too aware of the vital support that they offer. To the rest of society, they are the forgotten victims of crime. Through Restitute's work, they hope to change this (Restitute.org; 2021)

Cath Pickles (CEO at Restitute) delivered a powerful and personal story which centered around a young person's childhood history of sexual abuse and the impact that this had on both the young person and the parent responsible for their care. Cath has been contacted since delivering her presentation by conference attendees for advice and support.

Carer Awareness Training – Caring Together

Belinda Jones and Kerrie Campbell from Caring Together – a local organisation that provides support to carers – delivered an awareness training session to healthcare colleagues at the three acute hospitals. The training included statistics regarding the prevalence and demographics of carers, in addition to guidance on how carers can be identified and supported within a healthcare environment. Benefits to the NHS from consistent identification and support for carers were summarised to include the prevention of:

- Carers own physical and mental ill-health
- A caring crisis or breakdown in the caring situation
- Hospital admission/re-admission
- Admission to residential care and the need for emergency respite.

Caring Together have since delivered additional awareness training sessions for colleagues at the acute hospitals.

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Presentation recordings

Copies of the three presentations were made available to attendees after the event, and can be accessed via the following links:

Carers Passports presentation – Jodie Deards

Link to presentation recording: <https://youtu.be/63tHrCv0n4o>

Email address: Jodie.Deards1@nhs.net

Digital Inclusion work – Sarah Boyd

Link to presentation recording: <https://youtu.be/Vns7BPXbxJE>

Email address: Sarah.Boyd@nnuh.nhs.uk

Hidden Carers – Restitute – Cath Pickles

Link to presentation recording: <https://youtu.be/AyN8XSLYFg8>

Email address: ceo@restitute.org

Summary of Discussions and Themes

Key themes that emerged during the conference discussions for professional to take forward for action included the following:

- Early identification and involvement of carers (both adult and young carers) is paramount
- Carer awareness training should be mandatory for healthcare professionals
- Communications and information for carers must be ongoing so that are kept well informed regarding the healthcare management plans for their 'cared for'
- Particular attention needs to be given regarding carers involvement in the discharge planning process
- Carer information must be as accessible and as timely as possible
- We should not underestimate the impact that the caring role has on the carer and indeed the cared for (emotional, social, psychological, physical)
- Carers are the experts by experience and we need to enhance their voices and hence the recognition of what they do.

Carers' Stories

Two individual carers shared their lived experiences of caring for their husbands. The first story shared focused on the recent experiences of accessing services and the impact that the COVID -19 pandemic had with regards to the carer not being able to accompany her husband in the ambulance despite her husband having impaired cognition. In addition, the carer shared her thoughts of the discharge process and

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how this could have been improved to ensure that she was involved throughout the planning stage.

The second carer story centred around a patient admitted to hospital following a fall. Taking Covid into consideration, communications with the medical staff over the telephone were quite good and the carer was kept updated, however they felt that this did not allow the opportunity to prepare for the conversations and raise any relevant questions.

Similarly to the first story, discharge planning required further improvement to enable home (equipment) preparations by the carer to be expedited as the cared for was discharged very quickly, once medically fit. In addition, communication and information during the discharge planning phase was lacking.

Areas for learning included:

- Holding honest conversations with the carers
- Good liaison between GPs and Consultants
- Carer involvement to ensure that the Cared for gives the correct information about their condition on admission and future plans are discussed on discharge.
- Carers need to be enabled to accompany their loved ones when the cared for have cognitive impairment
- To be mindful that the Carer may also have health needs.

Closure pledges and evaluation survey results

Pledges

At the end of the conference, the hosting Trusts pledged to use the feedback and information gathered throughout the event to inform service improvement, and to hold a follow up event to share the actions taken and improvements implemented.

In addition to the Trusts' pledges, attendees were also asked which one thing they would do to support carers, following on from attending the conference. A range of the pledges made are shown below:

- “Ensure carers talk to GP for support”
- “Seek assurance more often about the way the hospital supports and engages carers in its services”
- “Continue to beat the drum for unpaid carers, highlighting their value and importance to the wellbeing of the people they care for and their own need for support and information.”
- “I have offered to share my experience and suggestions for improvement with Jodie Deards in her focus group.”
- “I will check with all my patients to see if they are a carer when doing my first discovery coaching session. I can now provide information of where to access help.”
- “I will always listen and value the carer as they are the experts.”
- “I will pass on relevant information to fellow carers and encourage them to put forward their own ideas or experiences to the relevant hospital trust in order to help them to understand how to improve the situation for carers and those they care for.”
- “Listen even more and ask how the person is even more.”
- “Try to seek out carers who might benefit from the information and help that is available.”
- “Keep listening to carers & their individual issues”

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Evaluation

Feedback was requested from attendees of the conference via online survey. 18 attendees completed this survey and the following summary can be drawn from the feedback (given by both carers and healthcare professionals):



Survey respondents highlighted that they particularly liked hearing the carers' experiences, that there was a variety of content, that the conference demonstrated there is dedication within the system to bringing about change for the better, and that the conference enabled sharing and collaboration of ideas across the region.

Topics of interest for further Carer events were also identified within the survey – these will be used to inform future collaborative events hosted by the acute hospitals.

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Next steps

This conference represented the first steps towards greater collaboration and consistency of experience of care for patients and carers across the three acute trusts in Norfolk and Waveney. This built on the development of greater and closer working between these trusts and also with community, mental health trusts and voluntary sector and social care partners.

The development of the Norfolk and Waveney Integrated Care System (ICS) affords an opportunity to really address the needs of carers consistently as a system.

A key commitment from all the partners is to work together to achieve this and a number of shared ambitions have been identified to take forward:

- Co-design and working in partnership with carers and carer support organisations will be central to how we work
- The key issues identified through the conference will be fed back into our individual organisations and collectively through our continued engagement collaborative.
- Outputs from the conference will be revisited at a future event in the Autumn where we will share progress and developments.
- A further conference will be planned - building on the success of this event with wider participation and involvement welcome.

In addition to the shared ambitions, each of the acute trusts have identified additional steps that will be taken following this conference, detailed in the following sections:

Queen Elizabeth Hospital King's Lynn (QEHL)

The learnings taken from this conference will be reviewed at the Patient and Carer Experience forum and will drive forward the desire to achieve the Carer Friendly Tick through fortnightly meetings with carers and local organisations to ensure carers remain front of mind

The Trust has long worked with West Norfolk Carers and is building links with other representative organisations and carers of all ages to develop services that meet their needs.

Carers Partnership agreements, strategy and policy will all be revised with carer input as will our web pages dedicated to carers.

A carer raising awareness training package is being developed with West Norfolk Carers for all staff.

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Norfolk and Norwich University Hospitals (NNUH)

The learning taken from this conference will be taken to the Carers Forum at the NNUH for further discussion and will be used alongside the results of the Trust's ongoing Carers Audit to inform actions to improve the identification and support of carers at the Trust. To find out more about joining the NNUH Carers Forum to work in partnership to improve the experience of Carers, please contact the hospital's Patient Engagement and Experience Team:

Email: Patient.Experience@nuh.nhs.uk

Telephone: 01603 288 295

NNUH will continue to work on projects that will improve the identification of carers and recording their carer status, whilst ensuring the voices of carers are embedded within service improvement projects at the Trust.

Carer awareness training will continue to be provided to trust staff.

James Paget University Hospital (JPUH)

The learning and key themes which emerged from the conference discussions will be taken to the Carer and Patient Experience Committee to help inform service improvements to enhance identification, recognition and available support for carers within the Trust.

The JPUH is committed to ensuring the voices of carers and patients become an integral thread to any service improvement and service delivery plans.

If you require this report in another format, please contact the Norfolk and Norwich Hospital's Patient Experience Team: Patient.Experience@nuh.nhs.uk