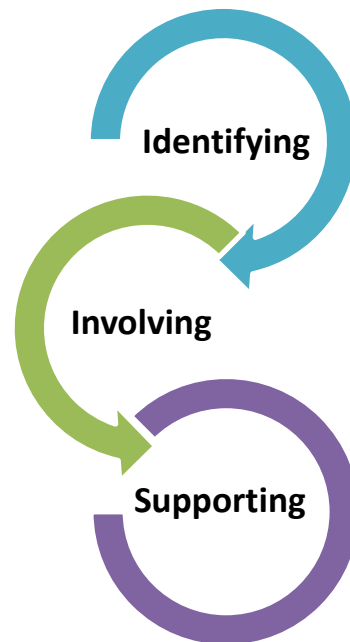


NHS Greater Glasgow and Clyde's preparation for the Carers (Scotland) Act, 2016

Executive Summary:
**Identifying, Involving and
Supporting carers in discussions
and decisions about the person
they care for, before they are
discharged from hospital.**



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Executive Summary: Community carer engagement report, March 2017

1. Background

The Carers (Scotland) Act (2016), introduced a number of provisions that will ensure carers and young carers are recognised and supported to continue caring. There is a specific duty within the Act to involve carers in hospital discharge arrangements for the person they care for. The focus of this research was to ascertain, from carers, what they believe to be good information provision and good involvement in care and hospital discharge decisions for the person they care for. Findings and recommendations will assist NHSGGC in identifying, involving and supporting carers within Acute Services and ensuring duties cited within the Carers Act are attained.

2. Methods

138 carers were recruited through existing third sector carer service training and support groups. A questionnaire was drafted that was used as a topic guide for discussion and could also be completed by participants. The majority of feedback was through group discussion and four questionnaires were self completed by carers at one participating group. In addition, one third sector carers' service conducted a focus group using the same questionnaire (6 participants). Time available for discussion varied from 10 to 90 minutes. Discussion groups ranged from 3 to 52 participants. Thematic analysis was conducted and responses were grouped into identified themes and presented. Quantitative presentation of feedback, in terms of frequency of comment, will relate to the number of participating groups where this information was highlighted and discussed.

3. Findings

3.1 Being informed

Carers do want to be kept informed when the person they care for is admitted to hospital. Information needs include treatment progress and outcomes, how the person they care for has slept, are they eating and drinking well and are they comfortable. Carers say they want sufficient information so they are prepared for the person they care for when they are discharged from hospital. Carers want hospital staff to be proactive in providing information and say they want this information to be easily understood, including using interpreters where this is required. Carers believe their role in communication between hospital staff and the person they care for should have greater importance. Equally carers want to be listened to, the carer knows the person they look after and have a good understanding of their needs and preferences. This is particularly relevant where there are capacity issues for the person they care for. Using other methods of communication should be considered, in particular the 'what matters to me' board that is in place across all hospital sites. Sufficient and relevant information provision, that is easily understood, and being listened to will acknowledge and value their role as a carer and increase their confidence to continue caring.

3.2 Being involved in care

There were mixed responses about being involved in the care of the person they care for while they were in hospital. Approximately one third of participating carers indicated they would like to be involved in providing care for the person they look after. The majority of carers were either hesitant or unsure if they want to provide care. Carers said that this would depend on the situation or if hospital staff requested their involvement. Carers would like to choose whether they want to be involved and that there is no pressure from staff to do so. In addition, carers want staff to understand that the carers' availability to provide care will vary. A small proportion of carers indicated that they would not want to be involved and believe that this is the role of ward staff. Obtaining better insight of the caring needs of the person they care for in preparation for going home and being able to provide continuity of care, are cited benefits from carers of being involved in care. Carers say that not having the confidence to look after the person they care for when they unwell and feeling that the carer is in the way are cited barriers to providing care.

3.3 Being involved in hospital discharge arrangements

The majority of carers say they want to be involved in decisions about hospital discharge arrangements for the person they care for. Carers say this should be as soon as possible and informing carers when the person they care for will be discharged. This will allow carers plenty of time to put in place any arrangements that were required, in particular if the carer works. Carers want to be central to any discussions about discharge planning, for example MDT meetings. Carers believe that staff should take account of what they know about the person they care for and the amount of care the carer is able to provide. This information will then influence any packages of care that are

required. Carers say that any support arrangements should be in place before the person they care for is discharged from hospital, for example, care package, adaptations and medication requirements. Carers say this should be in place in plenty of time to prevent delayed discharge. Once a date and time has been agreed for discharge this should not be unnecessarily delayed, for example awaiting medication to arrive from pharmacy.

4. High level recommendations

4.1 Being informed

- In order to effectively inform and involve carers, there is a need to be able to effectively identify and involve carers, to understand their needs and signpost carers to appropriate support. Therefore carer awareness training should be developed and delivered across the Acute Services. Carer feedback cited within this report should be used within the training. This should include a monitoring and evaluation framework to assess reach and impact.
- To consider reviewing communication protocols within the Acute Services that will ensure information provision meets the communication needs of carers so they feel sufficiently informed. This will include information that is understood and ensuring the Clear to All Policy and the Interpreting and Communication Support Policy are used. To explore communication methods such as the 'teach back' method, this confirms if information provided has been understood.

4.2 Being involved in care

- Implement NHSGGC's Welcoming Ward: Partners in Care vision where patients, family members or carers and hospital staff are partners in care, by facilitating carers' involvement in looking after the person they care for, while they are in hospital. Ensuring carers want to be involved and no pressure is exerted for them to do so. Where appropriate, being involved in care may prepare carers to provide care when the person they care for is discharged from hospital.

4.3 Being involved in hospital discharge arrangements.

- Hospital discharge protocols and procedures should be revisited to ensure carers are routinely involved in hospital discharge discussions and decisions for the person they care for. Indicative discharge period should be discussed indicating short, medium or longer term discharge period is likely. Agreed measures to monitor carer involvement for example written documentation and audit to ascertain carer satisfaction.
- Support requirements, that are required at home, should be in place before the cared for is discharged home, for example, care packages, adaptations and equipment.

5. Good practice points

5.1 Being informed

- To proactively and regularly inform and update carers about the person they care for. This will include updates and progress about their treatment and day to day information, for example have they slept well, eating well, are they comfortable.
- To acknowledge and value the carers' role and listen to what they know about the person they care for.
- To have greater awareness of the specific support and communication needs of people with specific conditions, for example Parkinson's disease.
- To consider how telephone contact with hospital wards can be improved.
- To work with carers to complete the 'what matters to me' board, ensuring the preferences for the person they care for are recorded and used.
- To consider other forms of communication that could be used to ensure carers are informed for example text messages, email, hospital discharge summary letter.

5.2 Being involved in care

- Hospital staff should ask carers, while the person they care for is in hospital, if they would like to be involved in their care planning.

5.3 Being involved in hospital discharge arrangements.

- Where possible carers should be involved in multi-disciplinary discharge discussions or any local arrangement for hospital discharge discussions about the person they care for.
- To ensure discharge medication is available for agreed day and time of hospital discharge to prevent avoidable delays.