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Research: Insight: Strategy.

Evaluation of the Carers Information Leaflet

Report for NHS Greater Glasgow & Clyde

SUBMITTED BY AXIOM

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1. Introduction and research objectives

1.1 Introduction

In recognition of the increasing reliance on informal carers, the Scottish Government introduced the Carers Scotland Act, 2016 which aims to provide more support to people who provide care for another individual (although not paid carer workers and volunteers).

The Act focuses on the impact caring has on the individual and ensures that their assessed needs are acknowledged separately from the needs of the cared-for individual. The Act also places a duty on NHS Boards to inform and involve carers in the discharge planning of the person they care for or intend to provide care for. Each Health Board must:

- Inform the carer, as soon as it is reasonably practical, of the intention to discharge the cared-for person
- Invite the carer to give views about their discharge
- Take account, as far as reasonable and practical to do so, of the carers' views in the decisions relating to the discharge.

Previous research conducted into the Carers' Pathway in the NHS Greater Glasgow and Clyde (NHS GGC) area highlighted different approaches to involving carers in discharge planning, with much of the discussions with carers focusing on patient issues rather than carer needs.

The feedback from carers suggested that much of the emphasis was on the impact of the carer's situation on the ability to successfully discharge the patient. Whilst important, it is not in keeping with the ethos of the Act and could lead to carer issues going undetected which in the long term could result in the admission of the carer to hospital and the re-admission of the person they care for. Therefore, the research also recommended that a more comprehensive exploration of caring responsibilities for the patient being admitted was needed by ward staff and that this should have a greater emphasis on the identification of carer physical and mental health, given that the NHGGC Adult Health and Wellbeing¹ Survey suggested that many carers had significant health issues of their own.

As a result of the research, and to support the implementation of the Act, a bid was submitted to Scottish Government to develop an information leaflet for carers, which would include details about the discharge process, whilst also highlighting available carer support.

A review of current documentation identified two existing sources – a discharge checklist created by East Dunbartonshire HSCP and a preparing for discharge document from South Sector Daily Dynamic Team. A draft leaflet was developed based on these documents, supplemented with information on support services and Power of Attorney.

¹ www.stor.scot.nhs.uk/handle/11289/579938

Following internal feedback, the final document was developed based on a tri-fold leaflet which aimed to encourage staff to engage with carers to discuss what elements might help achieve a good level of care at home (paid or unpaid). The leaflet sought to promote reflective thinking to enable better conversations between carers and staff whereby staff could build an accurate picture of the home situation and carers could clarify information regarding the patients' current situation.

Initial feedback from carers at the Renfrewshire Carer Centre was positive, with many pleased that estimated discharge dates were included in the information.

The final document was sent to Medical Illustrations to be produced and printed. Given cost implications, the decision was taken to make it black and white, however a coloured version was also produced for inclusion in the NHSGGC Carer website². A copy of the leaflet can be found in Appendix 2 in this report.

It was intended that the leaflet be given to family, friends and carers as soon as they become known to staff - this could be before a planned patient admission or immediately after admission to the ward/unit.

1.2 Research objectives

NHS GGC commissioned research to explore reaction to the document amongst carers, how it was being used, the difference it made to the relationship between staff and carers and the extent to which it had encouraged/enabled carers to link in with other carer services.

The research aimed to establish:

- To what extent the document met the needs of carers and how they were using it
- How it had been used in the wards
- What difference it was making to carer involvement in discharge planning
- Whether it delivered across all key stakeholders (carers and health care professionals) and across patient types
- What worked and what, if anything, were the challenges to it being used effectively
- What lessons can be learned from carers about how the document is communicated, issued and used
- What improvements should be considered which would ensure that the document is used effectively and meets carers needs
- Examples of good practice in implementation
- Key recommendations for future rollout.

² www.nhsggc.org.uk/your-health/health-services/carers/

2. Methodology

2.1 Research location

Four wards in the Royal Alexandra Hospital were selected to pilot the document:

- Ward 4 – Medicine for the Elderly (Stroke)
- Ward 7 – Medicine for the Elderly (Geriatric Orthopaedic Rehabilitation Unit)
- Ward 8 - General Medicine and Cardiology
- Ward 18 - General Medicine and Hematology.

The wards were selected due to the health conditions experienced by patients and their likely need for carer support following discharge.

2.2 Stakeholder groups

Discussions were conducted with the Programme Lead to explore the background to the document and how it had been launched. In order to explore the impact of the carer leaflet, a visit was planned for each location to speak with:

- Ward management (4 interviews)
- Ward staff who had been trained in the document and who were responsible for speaking to carers about patient discharge (8 interviews)
- Carers to explore their experiences (20 telephone interviews).

Topic guides were developed for use in the interviews with each stakeholder group. Copies of the guides are contained in Appendix 1.

Several visits were made to each of the wards in order to speak with ward managers and staff.

Challenges

Carers were to be recruited as part of the process of ward staff discussing the leaflet with them. Consent forms were included with the leaflet which asked carers to return completed consent forms to staff if they wished to take part. This would ensure that carers had provided consent to be contacted in line with the General Data Protection Register requirements. However, no completed consent forms were returned using this method. It was not known if this was due to reluctance of carers to take part in the research or an indication of low numbers of leaflets being issued to carers.

To address this, it was agreed that the research team would visit the wards to recruit carers directly. Although visits were made during the day, with the exception of Wards 4 and 7, the visitors who were available in the wards at this time tended not to be carers. Most of the patient carers in these wards were working and therefore visits were made to these wards in the evening to recruit carers.

Additional carers were also recruited through the Carers Reference Group in South Glasgow. Although these carers had not visited the four pilot wards, the person they had cared for had recently been admitted to hospital, enabling the research team to explore their discharge experiences and to determine their reaction to the usefulness of the leaflet.

Section 3 of this report outlines how it was anticipated that the leaflet would be used and the activities undertaken by the Programme Lead to support its launch. Page | 4

Section 4 outlines the approach taken to implementing the leaflet in each of the pilot locations and the challenges which arose, based on the feedback from ward management.

Sections 5 contains feedback from ward staff and carers on the approach to discharge and the use of the leaflet, with Section 6 outlining the recommendation from the research.

3. Anticipated use and pre-launch activity

Prior to the development of the leaflet, several approaches had been taken to ensure that hospital staff had an awareness of carers as well as the Health Board's responsibility to them. This included online training, onsite training, introduction of communication documentation within patient records, and development of direct access pathways for referrals via the Support and Information Services and the Carers Information Line.

Building on the previous research and documentation developed by East Dunbartonshire Health and Social Care Partnership and the South Sector Daily Dynamic Discharge workstream, a new document was created (a copy of the leaflet is in Appendix 2).

The leaflet, entitled "*Planning to Leave Hospital*" covers issues which are considered to be of interest to carers, including information on the Estimated Discharge Date. It also aims to prompt carers into giving ward staff information which they need to know when planning a patient's discharge including what happens at home, what support is provided for the patient, transport arrangements, medications, home care and follow up appointments. It also signposts the carer to sources of additional information or support.

In addition to this, the leaflet was supported by a communications campaign to help provide a "safe and timely discharge from hospital through involvement of carers". A Short Life Working Group was created with membership from Unscheduled Care, Health Improvement, Discharge Team, and the Glasgow City Health & Social Care Partnership. Communication included:

- Promotional Material within hospital discharge lounges which included a video and bespoke posters and information on the NHS GGC website
- Development of posters for easy signposting in Emergency Departments for staff
- A social media campaign, particularly aimed at people in the community who did not see themselves as carers.

3.1 Anticipated use

It was anticipated that the leaflet would be issued to family, friends or carers as soon as they have been identified by the ward staff as having a role in supporting patients at home or before their admission for elective surgery. The leaflet was expected to encourage a conversation between staff and family and carers about their caring roles and the issues they face. It was hoped that the leaflet would encourage families to see themselves in a caring role and to contact community-based support and information services for themselves and/or for the person they cared for to enable them to source support prior to or following patient discharge.

Copies of the leaflets were provided to each of the wards in numbers which reflected their varying levels of admissions and discharges. In the first 6 weeks following the launch, a total of 300 forms were provided to the wards. 251 patients were discharged from the four wards during this time.

3.2 Pre-launch activity

Prior to the beginning of the pilot, staff briefings occurred on all wards. In total 65 members of staff were spoken to in the initial round of training. There was also engagement with the following hospital-wide teams:

- Discharge Team
- Palliative Care Team
- Social Work
- Speech & Language
- Occupational Therapy
- Physiotherapy
- Practice Nurse Education Team.

Ward 8 and 18 also received additional training at the request of the Senior Charge Nurses with a further 27 staff members captured (totalling 94 individual staff members) as follows:

- 24 from Ward 4
- 15 from Ward 7
- 29 from Ward 8
- 21 from Ward 18
- 1 from Social Work
- 1 from Speech & Language
- 1 from Occupational Therapy
- 2 from the Discharge Team.

Staff trained included the Senior Charge Nurse in each ward, Nurses, Student Nurses, Doctors, Healthcare Support Workers, Occupational Therapists, Physiotherapists/Students/Assistants, Pharmacists/Technicians, Ward Clerks, Discharge Nurses and Speech & Language.

Training was provided by the Project Manager. It consisted of a 10 minute briefing, delivered in the ward, which was to cover the following learning outcomes:

- 1) Defining who a carer is under the Carers (Scotland) Act 2016
- 2) Describing staff responsibilities under the Act
- 3) Describing the delivery mechanism of the leaflet and the key points to highlight to carers
- 4) Understanding how the leaflet promotes communication between staff and carers
- 5) Knowledge of carer support available and referral/signposting mechanisms.

The focus of each session was also dictated by the staff group being trained. Particular emphasis was to be given to the reflective aspects of the document with social work and allied health profession (AHP) staff, who need a home-life picture to support patient discharge. The importance of discussing information surrounding transport arrangements and post-discharge medication was highlighted to nursing staff.

Leaflets were to be inserted into the front of each patient nursing file. In addition to this, staff were encouraged to give leaflets to any carer, family member or friend that was identified as visiting patients. Recognising that all carers are entitled to a basic level of support and information, this approach would allow wider distribution of the information and enable Carers Centres to establish the level of extra support to which people are entitled.

A poster for staff was created to explain the purpose of the pilot and indicate where it was taking place. These were distributed to wards and hospital-wide department offices. It was hoped that these would allow staff who had missed the staff briefing sessions to gain an understanding of the project.

The pilot was launched on June 3rd 2019, with nursing staff agreeing to distribute the leaflets. Each ward received appropriate stock levels to cover 1 month of patient discharges. A follow-up visit conducted in the first week after launch suggested that some leaflets had been issued in the wards, although it had not been used as part of a conversation regarding patient care.

4. Locations and implementation approach

Four locations had been chosen to pilot the "*Planning for Leaving Hospital*" leaflet. The wards were selected as they cared for patients who were likely to require support in the community due to their health conditions. The locations, all within the Royal Alexandra Hospital in Paisley, were:

- Ward 4 – Medicine for the Elderly (Stroke)
- Ward 7 – Medicine for the Elderly (Geriatric Orthopaedic Rehabilitation Unit)
- Ward 8 - General Medicine and Cardiology
- Ward 18 - General Medicine and Hematology.

An overview of their function and approach to using the leaflet is outlined below.

4.1 Locations

Ward 4 - Medicine for the Elderly, Stroke

Ward 4 is a 30 bedded ward which admits patients who have experienced a stroke and have a wide age range from younger working patients to more elderly, retired patients.

The ward takes admissions directly from Accident & Emergency (A&E), the Acute Medical Unit (AMU) and other receiving wards following triage. Patients can also be admitted to the ward from other NHS GGC hospitals (particularly the Queen Elizabeth University Hospital and the Vale of Leven) as well hospitals located in other health boards when they are ready for rehabilitation.

The length of stay for patients is variable, depending on their health needs, with a minimum of 7 days but generally longer. As with other Department of Medicine for the Elderly (DOME) wards, the ward staff includes a resident Social Worker.

Ward 7 - Medicine for the Elderly (Geriatric Orthopaedic Rehabilitation Unit)

Ward 7 is a 30 bedded ward which admits elderly patients for assessment and rehabilitation. As with Ward 4, patients can be admitted directly from A&E and AMU as well as hospitals within and outwith the Health Board area. Patient length of stay tends to be between 7 and 14 days and, as part of DOME (Department of Medicine for the Elderly), the ward also has access to a resident Social Worker.

Ward 8 - General Medicine and Cardiology

Ward 8 has 29 beds and admits patients with a range of health conditions, although most suffer from heart failure. The patients tend to be elderly with a range of co-morbidities, although the Cardiology patients tend to be those in their 40's and 50's and therefore, still of working age.

The length of stay in the ward varies, with elderly patients often remaining in the ward for a number of weeks due to higher levels of dependency.

Ward 18 - General Medicine and Haematology

Ward 18 is a 28 bedded ward which admits patients with a range of medical conditions including blood-related diseases. As a result, they have several patients with cancer and with blood infections and have patients covering a wide range of ages.

The nature of the diseases treated means that the length of stay varies considerably and can be as short as 1 or 2 days.

4.2 Implementation approach taken by each ward

Each ward took a different approach to the introduction of the leaflet based on what ward management considered to be most appropriate to their ward routines.

4.2.1 Ward 4

Storage

The leaflets are stored in a central drawer in the ward which is available to all staff and are also placed in the nursing admission document, the MAR (My Assessment Record).

Process of identification

Nursing staff should speak with patient and relatives when they are admitted to the ward. Due to the life-changing nature of the condition (stroke), discussions are held with all relatives to establish current and future support.

The ward has access to a resident social worker 5 days per week and all patients requiring additional support are referred to Ward Social Worker. The Social Worker discusses issues of concern with patient and carer/relatives and referrals are made to the Carer Centre for any carer/relative wishing additional support.

4.2.1 Ward 7

Storage

The leaflets are stored in the Senior Charge Nurse's office.

Process of identification

Relatives/carers should be identified during the ward admission process from discussions with the patient and/or relatives. To aid the identification process, it had been intended that Ward 7 would devote one member of staff to the pilot. However, this did not materialise due to staffing capacity issues. As a result, carers were identified by nursing staff and leaflets distributed by the Senior Charge Nurse.

4.2.3 Ward 8

Storage

The leaflets are stored in a poly-pocket folder in the front of each MAR.

Process of identification

Trained nursing staff should speak to patients about what support they receive as part of the ward admission process. This should apply to patients being transferred from another RAH ward as well as those being transferred from another hospital. Details on what support is provided and by whom should then be recorded in the Record of Communication with Relatives/Carers form.

Patients with health conditions who may be expected to have carers are also discussed at the Multi-Disciplinary Team (MDT) meeting which also acts as a prompt for staff to explore patients' discharge support needs. This discussion can also inform the discharge pathway with some patient being referred to the Palliative Care Unit as a result.

"For some reason, wards don't think of the Palliative Care Unit, they see it for cancer patients only. They don't see heart failure as terminal".

4.2.4 Ward 18

Storage

The leaflets are stored in a display rack on entry to the ward. The rack contains a wide range of other information leaflets aimed at relatives/carers and patients.

Process of identification

Nursing staff should speak with patients about what support they received and from whom when they are admitted to the ward. This should then be recorded in the NAD. The patients tend to be admitted to the ward without a relative/carer being present so there is a reliance on information from the patient about what care they receive. This should be confirmed with relatives/carers when they visit/contact the ward post-admission.

5. Evaluation feedback - staff

Discussions were held with a sample staff in each of the four wards. The staff interviewed included nursing staff and a member of the ward-based social work team.

Visits were also made to the wards to speak with staff and telephone interviews were conducted with relatives of patients in each of the pilot wards as well as relatives of other patients recently discharged from hospital. The patients reflected a cross-section of males and females, aging from early 30s to late 80's and with a range of health conditions including cancer, heart failure, strokes and dementia.

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The discussions focused on the following issues:

- How staff identify who has a caring role
- Who is responsible for doing this
- How is this recorded
- Content of discussion
- Understanding of the role of the leaflet
- How the leaflet is used
- Challenges using the leaflet
- Extent to which it meets carers/relatives needs.

5.1 How staff identify who has a caring role

Whilst it was intended that the discussion takes place on admission, the staff feedback suggested that any contact with relatives generally takes place some time after the patient is admitted to the ward. For many of the patients who are admitted to the wards, they have been transferred from another ward or hospital and, despite a structured admission process, they receive little information on the patient's relatives or caring situation. The MAR contains questions to identify informal carers for the patient on admission. This information should be passed to receiving wards. However evidence suggests that these question are not always completed on admission and are unlikely to be followed up on the ward.

The delay to the identification appears to relate to the state of the patient's health on admission to the ward and also their perceived level of dependency – in some cases, this is a ward decision not to discuss issues until the rehabilitation plan is known and in other cases, it appears to be due to a continued reliance on patient's identifying their need for support in the home and who provides this. As these interviewees commented:

"We wouldn't know if a relative was providing care or support unless the patient told us this"

"We often can't get the information on what support they receive or who cares from them as the patient can be too ill to give us this when they arrive on the ward".

"I don't think any of our patients at the moment have informal carers, although we would only really know this if the patient mentioned it".

Whilst some interviewees recognised the desire to gather the details on carers/relatives' support on admission, it can be often the case that the carer/relative is not present at admission.

Whilst the training provided pre-launch emphasised the range of people who could have a caring role, feedback from some of the staff suggested that identification of people who may provide support or have a caring role is patient-driven, with patient age and health condition playing a key role in staff perception of who may be receiving support at home, as these comments indicate:

“Some of the patients with heart conditions are unlikely to have carers as they are much younger”

“Older patients tend to be more dependent on family and friends and they tend to have carers”

Staff were also concerned that carers/family were often reluctant to accept that the patient was ready for discharge and that this often triggers the discussion over support provided in the home. The carer/relative reaction to the discharge news may indicate that the leaflet discussion is in fact conducted when discharge is imminent rather than on, or immediately following admission. It is not clear to what extent the leaflet is used in all cases to prompt the discussion.

5.2 Who is responsible for identifying carers/relatives with a caring role

The responsibilities for identifying who had caring responsibilities appeared to vary by ward. Whilst trained nursing staff undertook ward admission, in some cases, it was Physiotherapy or Occupational Therapy staff who would discuss current support provision and future patient support needs with families and carers. The Physio and OT staff prepare the care plan. They conduct a risk assessment and outline what is needed for patient discharge. As a result, they appear to have the most discussions with relatives and carers pre-discharge. Although some OT/Physiotherapy staff received training on the leaflet, interviewees were not sure how much the OT and Physio teams knew about the leaflet and were not certain if they were using it in their discussions with patients.

5.3 How caring responsibilities are recorded

It was intended that caring responsibility be recorded in the MAR. However in cases where the discussions are conducted by hospital OTs, nursing personnel may not know who had caring roles for patients. Indeed, a short review of nursing documentation during some ward visits for the evaluation did highlight variations in the extent of information in the nursing documentation.

5.4 Content of discussion

From staff feedback, much of the discussion appears to be around what needs to be done to support the patient's discharge, although the feedback from staff suggested that the leaflet

is not generally used to prompt this. Feedback from some interviewees indicated that advising carers/relatives of the estimated date of discharge was often the catalyst for carers/relatives raising concerns, particularly amongst relatives of patients with deteriorating health conditions. This suggests that the leaflet is not the basis for the discussion, despite providing an opportunity to raise the topic of Estimated Discharge Date.

Some interviewees also felt that carers were more interested in the patients' health and were reluctant to discuss their own issues. The feedback from staff suggests that the extent to which staff probe carer/relatives to identify what support they may need is highly variable. Interviewees who suggested a greater level of discussion with carers/relatives about issues concerning them tended to be those who had caring experience of their own or who had a caring role in previous employment.

In wards with social work support, social workers explored support and safety issues with relatives, carers and patients and made referrals for fire safety assessments, money advice services, community social work and the carer centre. Recognising that many people do not see themselves as carers, the discussions tended to commence with issues around emergency planning and what would happen in situations where the family member took ill.

5.5 Understanding the role of the leaflet

Awareness and understanding of the role of the leaflet was mixed across all four wards. Awareness was best amongst staff in Ward 8 where the leaflet was placed at the front of the patient file as intended. Whilst ward management in the other three wards were clear as to the purpose of the leaflet, awareness was mixed amongst staff.

Feedback from ward management and staff in all wards suggested that not everyone was clear regarding who the leaflet was aimed at. This interviewee's response was reflective of the feedback from several interviewees:

"I can't really remember who all was to get the leaflet. I think it is the carer or relative but I am not sure if it is everyone who visits the ward".

It was also apparent from the interviews that, whilst ward social work staff were discussing issues with carers, the discussions were taking place without the leaflet as they were unaware of its existence.

5.6 How the leaflet is used

Use of the leaflet varied across all four wards and also amongst staff in the same ward. In some cases, staff indicated that the leaflet would be given to carers/relatives on admission. In other cases, where the length of stay is likely to be longer, the leaflet is given to carers/relatives nearer the time for discharge. Staff were reluctant to discuss issues of discharge too early as they felt it created anxiety amongst relatives that the person they cared for would be discharged imminently.

Some staff suggested that the leaflet was given out along with a range of other leaflets and not specifically discussed with the person, as this interviewee commented:

“There is a lot of information to draw their attention to....we get visits from other hospital departments and they all want us to talk to relatives about their leaflets. It’s just not possible”

Some interviewees expressed concern at the amount of information carers are given:

“I think we are in danger of bombarding them with information at a time when they are concerned about their family member. There are about 15 information leaflets that we are expected to give them..... it’s way too much”.

Another reason given by staff for not using the leaflet in discussions with carers was that they felt that their existing approach was of more benefit as it focused on discussions around specific health conditions which often prompted carer concerns regarding discharge and support following discharge.

5.7 Challenges using the leaflet

Staff availability

A key issue raised by ward staff which impacted on their use of the leaflet was staffing numbers. As one interviewee commented:

“We have 7 or 8 patients in our care on day shift which means it is not always possible to speak to everyone individually”

Staff changes

There have been several new staff starting in the wards. Whilst the Project Manager has conducted local training on the leaflet, the numbers of new starts has proved challenging for ward management to ensure that they are all familiar with the leaflet.

Ward management also highlighted a general lack of carer issues amongst new recruits. Feedback from new staff who had recently attended a Health Board and Ward induction suggested that the issue of carers is not specifically addressed. As one interviewee indicated:

“There is over 400 at the Health Board induction... it’s more of a corporate induction and didn’t talk about carers as far as I can remember. You do get a lot of information and it’s quite a lot to take in at once so maybe they did mention it but I can’t recall any information being given”.

“The ward induction tended to focus on care planning. I can’t think of anything about carer issues or the leaflet”.

Ward management also suggested that more focus is needed for student nurses on carers and the issues they face. As one interviewee commented:

“The focus is all on the health condition. The students don’t see the bigger picture and they don’t understand the issues relatives face in coping with people with life-changing health conditions”.

Extent of information

Carers appear to be given a considerable amount of information during the patients’ hospital stay and pre-discharge. As these interviewees commented:

“We seem to have to give them leaflets for everything now – it is far too much information for them to take in and you often find that they have thrown the leaflets away when they get out of the ward”

“We have to give them information on the Norovirus, Washing Clothes at Home, Reducing Your Risk of Blood Clot, Bed Rails, Peripheral Venous Catheter, Prevention and Control of Infection, MRSA, Spiritual Care, Preventing Pressure Ulcers, Reducing Falls, the Complaints Procedure, Adults with Incapacity, Food and Health as well as the carer leaflet. Is it any wonder the carers don't take it in”

There is also a lot of information posted on ward walls which aim to give patients and carers additional information. Whilst the carer leaflet poster is displayed it is one of several.

“We have loads of posters I don’t think people see them when they come in – they are more interested in how their relative is doing”

Timing of discussion

Some interviewees highlighted the need to raise the issue of support needed following discharge with relatives several times, as this interviewee explained:

“People are in crisis and they are often not taking in what you are saying ...you need to give them time to get used to things”

5.8 Extent to which the leaflet meets carers/relatives’ needs

“I am not sure it really helps that much. We had a wife who was an informal carer and we spoke about services which could help her but all she was really interested in was befriending. We did direct her to the Carer Centre to see if they could help as we can’t organise this”.

In some cases, staff were aware of examples where the leaflet had been useful in supporting families to access help.

“We had a wife who has very worried about finances as her husband would have to give up work due to his health. I spoke to her and gave her the leaflet and referred her to the Carers Centre. She mentioned to me that they had been really helpful and had linked her up with benefits services and money advice”.

6. Evaluation feedback - Carers

Telephone interviews were conducted with 18 relatives of patients, all of whom had a caring role for their family member. Nine of these interviewees were relatives of patients in each of the pilot wards. Nine interviewees were relatives of other patients recently discharged from hospital, primarily the Queen Elizabeth University Hospital.

The patients cared for reflected a cross-section of males and females, ageing from early 30s to late 80's and with a range of health conditions including cancer, heart failure, strokes and dementia. Ten of the 18 patients cared for had been admitted as an emergency. Eight were planned admissions.

The carers interviewees included wives, husbands, mothers, daughters, sons and neighbours. Ten out of the 18 carers were in current employment. One interviewee looked after their grandchildren from home. The remaining 7 interviewees were retired.

The discussions focused on the following issues:

- When do staff identify who has a caring role
- Involvement of relatives in planning discussions
- Awareness and understanding of the leaflet
- Reaction to the leaflet
- How the leaflet has been used
- Benefits of the leaflet
- Preferred topics for inclusion.

6.1 When staff identify who has a caring role

The feedback from the carers interviewed indicated considerable variation in the approach taken to identifying who cared for patients admitted to the wards. This included both pilot wards and wards in other hospitals.

6.1.1 Pilot wards

Interviewees from the pilot wards confirmed that staff did speak to them in connection with establishing what support the patient received at home but that this tended to take place some time after admission, most often just prior to discharge, with either a member of the nursing staff, Occupational Therapists or Social Workers.

In four out of the nine interviewees, the relative/carer was approached as a result of staff discussion with the patient to determine what support was provided at home or to determine the patient's living arrangements (in the case of stroke patients and those with dementia). Two interviewees expressed concern at the reliance on information from patients to identify carers as this had resulted in people being wrongly recorded as carers, as this interviewee explained:

“My (relative) told nursing staff that (NAME) was a carer when in actual fact the person is a keyholder. She has her own health issues and is at home all the time and lives next door so she keeps a key. It’s not really a caring role”

“My (relative) told the ward that my brother was caring for her when in fact it is me as I live nearer. This caused a lot of problems as I was not getting any information on how (NAME) was doing and what the plans were for them”.

In three cases, the ward staff initiated the discussion with the relative/carer. These interviewees were relatives of stroke patients who were going to require a considerable change in their living circumstances in order to return home.

“The Social Worker approached me in the ward and asked if she could talk to me about (NAME) and how things were. I was really grateful for this as I was in complete shock and hadn’t really thought about the future”.

In the remaining two cases, the relatives had approached ward staff themselves with concerns about how they would support the patient after discharge.

6.1.2 Other wards

For those who had been admitted as an emergency, discussions with nursing staff tended to focus on the patient’s health issues and establishing the first point of contact. Interviewees did not feel that there was any attempt at this stage to determine if the patient had anyone providing care and support at home, as this interviewee explained:

“They wanted to know my husband’s details and what had happened as well as previous health history. They asked who I was and put me down as a contact but didn’t ask anything about any support I provided for my husband”

There were also three interviewees (one spouse and two daughters) who stated that there had been no contact with them regarding their caring role following an emergency admission or during any of their visits to the wards and that, in fact, their relatives had been transferred to other wards (or in one case another facility) without advising them or anyone in the families.

For those brought into hospital as a planned admission, much of the discussion also focused on the patient’s health. Where there were initial discussions with the relative about their caring role, this appeared to be in cases where the patient was a re-admission and known to ward staff.

6.2 Carer involvement in planning discussions

Five out of 18 interviewees stated that they had been involved by ward staff in planning for their relatives’ discharge. Three were relatives of people who had been admitted to Ward 4 and two were relatives of people admitted to Ward 8 in the RAH (both pilot wards). They had been approached by ward management or a member of the nursing team to talk to

them about the implications of the patients' health conditions and what implications this would have for their living arrangements. As one interviewee commented:

"(Staff name) came up to talk to me on one of my visits. We have a long chat about (NAME)'s health and what this would mean when he came home. I had no idea what I was going to do but the nurse said that there was help for me. The next day (NAME) the Social Worker saw me on the ward and she was so helpful. To be honest I would say she did my thinking for me. We talked a lot about what I needed to help me, which was great"

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None of the 4 other interviewees from pilot wards or the interviewees from other wards felt that they had been involved by ward staff in planning discussions about their relative/neighbour. In two cases the patients had been moved without the knowledge of their relatives/carers and in another case a patient had been discharged without arrangements being made to re-instate their home meal visits. However, it should be noted that none of these situations involved patients in any of the pilot wards.

Interviewees, including those from the pilot wards, felt that staff were reluctant to speak to them and they felt it was left to the last possible minute before issues regarding discharge dates were discussed. As this interviewee explained:

"I didn't know (NAME) was being discharged until the day before. (NAME) is unsteady on his feet and gets quite anxious so it's important that I am there when he gets home and I can get him settled and get shopping in and the like. I work as well and it was a real hassle trying to get time off to be there for him....my work are really good but they need a bit of warning so they have cover when I am off".

"They did speak to me but I didn't think they listened. I felt it was all about getting (NAME) off the ward and not so much about what I needed. I've got asthma and rushing about it not good for me and I get stressed really easily so I like to know in advance what is happening. I don't think the staff were really interested in my health, it was all about (NAME)"

6.3 Awareness and understanding of the leaflet

Of the nine interviewees from the pilot wards, only two could recall receiving the leaflet. None of the other 7 interviewees were aware of it. As this interviewee commented:

"My wife was in the ward for 6 days – I did speak to one or two of the nurses but no-one mentioned a leaflet for me. They did talk to me a couple of days before to tell me my wife would be probably getting home but I didn't get a leaflet".

The two interviewees who could recall the leaflet were interviewees from Wards 4 and 8. Both interviewees received the leaflet from nursing staff. The interviewee from Ward 4 said that she was given it a few days after her relative had been admitted and was told that it would give her some information and things to think about before her relative came home. She thought the leaflet had been given to her about three weeks before discharge.

The interviewee from Ward 8 had been given the leaflet as part of a bundle of information leaflets a few days before their relative was discharged. She could not remember if the nurse had mentioned it to her but she saw it amongst the other leaflets when she got home. She thought that it was information to help guide her in what she needed to know before her relative came home.

6.4 Reaction to the leaflet

Interviewees were given a copy of the leaflet prior to taking part in the interviews. This ensured that people who were not familiar with it had an opportunity to review it. All of the interviewees thought that the leaflet contained information which was useful.

Rather than seeing it as a leaflet which should be given out pre-discharge, the interviewees thought that it was intended to be given to people either prior to patients being admitted (for elective admissions) or immediately on admission, as this interviewee explained:

"The introduction says that it is to help you think about different things when someone is in hospitalthat suggests that you should see it quite early on to give you time to think about things".

Interviewees found the information it contained useful, particularly in prompting them to think about what support someone actually needs as well as who provides it. Many of their comments suggested that it helped them realise that they provided support and were actually considered to be a carer.

"When it's someone in your family you do whatever is needed to help them and you don't see this as caring. The leaflet actually is really useful in getting you to think about what you do and if you need any help doing it"

"I could have done with this a few months ago as I look after my husband and didn't know what help I could get".

The interviewees also found it helpful that it covered a range of topics, including what patients would need, transport and where to pick them up. As one interviewee observed:

"These are things you don't think about and then stress you out when you go to pick someone up".

Interviewees also found the information on the information the patient should get before they leave also useful.

"The stuff about the fit note is good - I have had times when my husband has left the ward without this and the hassle this has created in getting one afterwards was unbelievable. I know to make sure he has it now but this would have prevented a lot of grief had I known this then. The staff don't think to tell you"

"Even something like do they know how to use any medications. My husband had dementia and the answer to that was no but the ward never said anything to me about the medication he was on. I never thought to ask either"

It is interesting to note, that none of the interviewees mentioned any issues with the provision of another information leaflet, despite the concerns raised by ward staff as to the amount of information received. Although, the carers interviewed were not aware of the range of information leaflets they should be receiving, they felt that the Planning for Leaving Hospital leaflet was of particular benefit to carers and one which staff should make carers aware.

6.5 How the leaflet has been used

Although only two people interviewed were aware of the leaflet, both had used the leaflet as a prompt for further action. One interviewee had contacted the carers centre and had been referred to money advice services and the other interviewee had spoken to the ward about their relative's medication. Both carers suggested that the leaflet had given them the confidence to raise issues which were concerning them.

"I didn't realise I was entitled to financial support. No-one in the ward spoke to me about the leaflet but I saw that it asked if anything was worrying me and I was worried about how I was going to cope with the bills since my husband can't work the same. So I gave the Carers Centre a call and they were great. I don't know if I would have mentioned it to anyone if I hadn't seen it in the leaflet"

"I was concerned that my husband would not take his medication when I was out at work so I spoke with one of the nurses and they got a doctor to speak to me and we have sorted out when he has to take his tablets so that I am around to make sure he does".

6.6 Benefits of the leaflet

All of the interviewees suggested that the leaflet would be useful for relatives to have. Its overriding benefit being that of raising people's awareness of their potential caring role. As these interviewees commented

"It would have helped me realise that I am a carer not just (NAME)'s wife. I think that would have made me more likely to ask for help as I can see now that I could be entitled to support to help me look after (NAME)"

The leaflet was also seen as providing a catalyst for people to take action, providing a starting point of where to get information or help, as these interviewees suggested:

"You just get on with it. You can feel quite lonely at times and you don't always know where to go to ask. You don't always have the time to think as you are too busy getting through the day. The leaflet seems to help you think things through and decide what you want to talk about"

"I don't have a clue about what is out there. I didn't even know there was a Carers Centre locally till now".

Another key benefit of the leaflet which was raised by many of the interviewees was that it gave legitimacy to their concerns and suggested it was OK to talk to hospital staff about them.

"The very fact there is a leaflet says to you it's OK to be worried and it is OK to ask. I think that is really important. You don't want to take up ward staff time as they are very busy but they are sometimes the only people you can ask – the only people you know are there to ask"

"I don't think you are really encouraged by hospital staff to talk about you. They are there for the patient and they don't seem to have any thought for the families. The leaflet is good in that it says to you – go and ask, go and talk to them about what you are dealing with, get help".

6.7 Topics for inclusion

The issues concerning the interviewees did vary considerably, depending on their personal circumstances. However, the most common concerns related to:

- Their own health and their ability to cope looking after their relatives (older carers)
- The suitability of their housing longer term to sustain their relative in their own home
- Money and financial security.

As these interviewees explained:

"I'm getting older and I am not very steady on my feet myself. I get so tired and looking after (NAME) is all day, every day"

"We have stairs in our house and although we can get some adaptations as he gets worse I don't think our house will be suitable for him. I really don't want him stuck in one room but I can see that happening"

"Money was a real issue because my husband can't work now"

Many of the interviewees recognised that the range of issues is considerable and that it would not be possible to cover everything. The views of this interviewee are reflective of the majority of carers spoken to in this evaluation:

"It is not so much about including everything, but about making sure people get the leaflet and get the chance to think about what is important to them. The leaflet as it is could maybe cover money and carer health more specifically but as long as it is clear in the leaflet that it is OK to ask, I don't think the topics are that important".

7. Conclusions and recommendations

7.1 Conclusions

The feedback from the carers who participated in this evaluation has suggested that the “Planning for Leaving Hospital” leaflet could provide a useful support for people who have a caring role. It appears to help people who support individuals to live in the community to recognise themselves as carers, think about the issues affecting them and giving them the confidence to talk to others about their caring role. The interviewees found it beneficial to have a leaflet which focused on them and which encouraged them to raise their concerns.

Whilst only a few carers recalled receiving the leaflet, it had resulted in them taking action to look for support for them in their caring role.

Unfortunately, the impact of the leaflet has potentially been minimised as a result of limited use by the pilot wards. The feedback from the wards and the carers interviewed from these wards suggests that the leaflet has not been used as intended. There has been little conversation by ward staff with families/relatives using the leaflet. At best, the leaflet has been included in a range of information given to families/relatives. In some cases, this may be due to a perception that the current process for engaging with carers is effective. But in many cases, it has not been included in either the admission or discharge process.

The usage data from the Project Manager, which is based on the extent of ward re-ordering of the leaflet, would appear to confirm its limited issue and therefore use. The limited awareness of the leaflet, what it was trying to achieve and how it was to be used amongst ward staff in this evaluation also appears to confirm its limited implementation. This would suggest that the following factors will be essential in any future roll-out:

- Buy in from ward/unit management
- Improved understanding of ward staff of the Carers Scotland Act, 2016
- Visibility of the leaflet to ward/unit staff.

7.1.1 Buy in from ward/unit management

In order for patients to get the leaflet, it needs to be built into ward processes and routines. This requires involvement of ward/unit management both initially to introduce the leaflet into their ward and in the longer term to ensure its use is sustained and becomes local practice.

7.1.2 Improved understanding of the Carers Scotland Act

The feedback from ward staff in this evaluation did not indicate an understanding that the Carers Scotland Act required health boards and health practitioners to consider the needs of carers. Feedback from new recruits and trainees suggested that carers do not receive sufficient profile in either the corporate or local inductions. As a result, despite the Act being in place for over three years, local practice is still not sufficiently or consistently engaging them in discharge planning.

7.1.3 Visibility of the leaflet to ward/unit staff

It is recognised that the use of the leaflet is new to ward staff. In three of the pilot locations, the leaflet was stored in places which were not regularly visible to ward personnel. Storage in the Senior Charge Nurse's office means that the leaflet is not visible to staff. The office is often also used for meetings meaning that the leaflet is not always available to staff. Storage in a central drawer or in the general leaflet display board limits its visibility to staff as it is one of many leaflets for patients and families.

7.2 Recommendations

Whilst the impact of the leaflet has been hampered by inconsistent and limited issue from wards, the feedback from the carers who participated in this evaluation suggests that it is a useful document and should be considered for wider issue. To maximise its effectiveness, based on the carer feedback from this evaluation, we would recommend consideration of the following:

7.8.1 Issue timing

The interviewees stated that the most important aspect going forward was to make sure every carer got a copy of the leaflet. They felt that one of its greatest advantages was that it provided families with an opportunity to reflect on their situation and recognise their caring role, something which many do not see themselves in at present. As these carers commented:

"People need to see that they are carers. I think ward staff can assume who has a caring role and may be pick and chose who gets information at the moment. I don't think they really see the extent of work families do to keep people in their own home"

"If everyone got this they could decide for themselves what they wanted to do"

In addition to families not perceiving themselves as carers, the feedback from ward staff suggested that some may be assuming patients don't have carers due to their age, as some staff thought some patients were too "too young" to have carers. As a result, these patients' carers remained unidentified in the ward.

To support this wider identification of potential carers, the interviewees thought that the leaflet should be given to families/relatives in the first few days after admission but not necessarily as part of the admission process.

"I think giving to someone just as their relative is admitted to the ward might give off the wrong message – it kind of smacks ofwe are going to get them out ASAP"

"If the person is not a regular attender at a ward then I don't think families would take in the information straight away – they are still trying to come to terms with the admission. Maybe a couple of days later"

“It would be better if they just gave it to everyone and not try and decide who should get it. It might mean that someone gets it who isn’t a carer but if they pass it on to someone who is, does it really matter?”

7.8.2 Issue method

The interviewees thought that giving relatives a hard copy initially and then following this up with a conversation at a later stage would be the most helpful. Page | 24

“I think people need time to think things over. There is a lot going on and I think people maybe need the issue raised a few times before they really can think through what they need”

“If we got the leaflet we could look at it and think about what is concerning us”

The need for reflection is perhaps not surprising since most family members do not consider themselves to be carers. They will need time to consider their role and whether this is a caring one.

The conversation with ward staff was also seen as being of particular importance:

“It is not enough just to hand out a leaflet and think that’s me told you. It kind of still puts the emphasis on the person to follow it up. It also still gives the impression that the patient is the most important and that ward staff don’t think they need to speak to families”.

“I think people need reassured it is OK to raise concerns – people are more focused on the patient and less on themselves. Talking to ward staff about what their relative is likely to be like when they get them home makes it seem like the family’s situation is important too”

This suggests that it is not sufficient to hand the leaflet out without some kind of follow up. Aside from carers needing time for reflection they may also need more prompting to fully consider the issues they are facing. The variety of issues could not be adequately reflected in a leaflet, therefore staff discussion is vital.

7.8.3 Content of discussion

Whilst the leaflet can start the process of people considering if they have a caring role, it cannot reflect all the issues which may arise from a patient being discharged into someone’s care. This needs to be covered through a discussion with ward staff if the Health Board is to fully meet the requirement of the Carers Scotland Act. Only through relatives being made aware of the support a patient may need on discharge can they fully consider what this means for their own health and wellbeing and ongoing support needs.

Given the feedback from carers, it would make sense for this discussion to take place after issuance of the leaflet.

Finally

It was clear from the feedback from carers in this evaluation that the Planning for Leaving Hospital leaflet is considered of benefit to carers, enabling them to fully consider their role. These recommendations are intended to maximise its benefit and enhance its effectiveness in any future roll out across the NHS GGC area.

Appendix 1: Topic guides

Some questions to prompt discussions with carers

Exploring what happens just now

- What contact do they have from ward staff when the person they care for is in hospital
- What do the staff talk to them about
- When does this happen (eg on admission to the ward, a few days before discharge, on the day of discharge)

Exploring what they would find useful

- What would it be useful for ward staff to talk to them about
 - What information do they need about the discharge of the person they care for
- When should this be done (eg on admission to the ward, a few days before discharge etc)
- How should it be done (eg by telephone, during a ward visit etc)

Exploring their views on the Health Board's plan for involving carers

- Is this something the Health Board should be doing
 - What do they think the hospital needs to do better/more of to ensure it happens
- If it not something they think the Health Board should be doing, explore why not

Exploring their views on the leaflet

- Is this something they would find useful
- When would it be useful for them to get it

ASK IF WILLING TO TAKE A LEAFLET AND TO SPEAK WITH AXIOM IN A FEW DAYS ABOUT WHAT THEY THINK OF IT

Draft Discussion Guide for Ward Managers

1. Introduction

- Introductions
- Purpose of discussion
- Explain background to research and Axiom's role and outline research programme
- Explain that all comments made are strictly confidential and will not be attributed to participating individuals

2. Discussion topics

Background

- Understanding of the concept behind the Carers Handheld Document
- Who has received training and how were they selected

Implementation

- Who issues the documents and why have they been selected (if not all staff on ward)
- How do staff become aware of people who have a caring role for patients
- How are staff expected to provide carers with the document
 - How do they decide which carers are given the document
 - When is it given to carers
 - How is it issued (probe for any conversations)
 - Where is it stored
- How do they (the ward manager) ensure this happens
- What do staff tell carers about the document and the pilot
- How do carers react when offered the document
- What happens after the document is issued
 - What is recorded after discussion
 - Where is this recorded
- What makes the process work in their area
- The benefits resulting from the approach for carers, patients and staff compared to what happened pre-discharge before the introduction of the document (probing for improvements in communication, relationship building etc)
- What difficulties have there been to implementing the process
 - How have these been addressed/are being addressed
- What, if any changes have been made to ward/unit routines/staff practice to ensure carers receive the document and what are the implications of this
- Anything which could have been done differently and which would improve the use of the document for carers or staff.

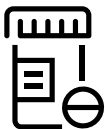
Winding up

Summarise key views expressed during interview. Thank interviewee for their views and close

Appendix 2: Planning for Leaving Hospital Leaflet

Before you leave...

When the patient is discharged they will be given a discharge letter, a 7 day supply of any new medication and instructions on any follow up care that they need.



We know that there might be a lot of information given to you. Here are some important things to think about

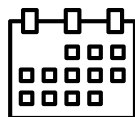
- Do you and the patient know how to use any new medications or equipment?

- Does the patient need a fit note? (This is a letter from the hospital to give to an employer if the patient has missed work or will need to have some time off)



- Have you or the patient been given a hospital discharge letter?

- Are there new care packages starting?



- Are there any follow up appointments to go to?

- Do you have contact information for any services you need to contact like social work, homecare providers and carers services?

You can write down any numbers here:

Contact Information

If you have any questions or concerns about the hospital stay or the discharge plan please speak to the ward staff.

The name of ward the patient is on is:

The telephone number for the ward is:

The Senior Charge Nurse on the ward is:

If there are any problems following discharge then please contact your GP or phone NHS 24 on 111.

Need more help?

The Support and Information Service is provided by NHS Greater Glasgow and Clyde with centres in Queen Elizabeth University Hospital, New Victoria, Stobhill, Glasgow Royal Infirmary and Royal Hospital for Children. It is available to all hospital users including patients, visitors and staff. A wide range of support is available **including money advice and carers support.**

Alternatively you can contact them via

Phone: 0141 452 2387

Email: SIS@ggc.scot.nhs.uk

This leaflet has been made with input from East Dunbartonshire Public, Service User and Carer Representatives Group and NHSGGC South Sector Unscheduled Care.

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Planning For Leaving Hospital

Information for family, friends and carers

We know that looking after someone can require a lot of time and energy. If you feel like you may need some extra support you can contact your local Carers Services.

They can give you help with:

- Emotional Support
- Money Matters
- Short Breaks
- Training
- Having A Voice

You can call the **Carers Information Line on 0141 353 6504**

They will direct you to your local service.

You can also find information on our website: www.nhsggc.org.uk/carers



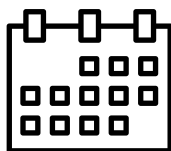
In this leaflet you will find information about different things to think about while someone is in hospital. This will help us work with you to create care plans, as well as discharge plans for the patient.

Working Together

We want to make sure that all our patients are supported while they are in hospital and when they leave. Friends and family play an important role in this and we want to work with everyone to make sure that patients receive the best care possible.



If you have Power of Attorney or Guardianship of the patient then please let us know as soon as possible. Please also bring in a copy of the document.



Estimated Discharge Date

We will give you an Estimated Discharge Date (sometimes called the EDD) as soon as possible – this is the day that we think the patient will be able to leave hospital. This date may change, however we will let you know if this happens. We hope that by giving everyone this information it will be easier to plan for the patient coming home.

You can keep a note of the Estimated Discharge Date here:

What is important to you?

We know that patients usually make a quicker recovery once they have left hospital. But before patients can be discharged, we need to make sure there is a plan in place so that both you and the patient are supported once they leave.

We want to know how you feel about your caring responsibilities and if you think you may need some extra support. Your health and wellbeing is very important to us.

To start with it would help if you could tell us what life is like at home just now. Here are some ideas of things to think about

- Do you give the patient any help e.g. making meals, helping them get up?
- Do you have any help from community services e.g. community nurses, homecare, volunteers, social services?
- Do you feel supported at home?
- Do you feel like you have a balance between your personal life and your caring responsibilities?
- Do you worry about how you will cope after the patient is discharged?

You can use this space to write down what life is like and discuss it with ward staff.

Other things to think about...

Transport Home

You and the patient need to make your own transport arrangements to get home. We can arrange a taxi but **we cannot pay for it**. If patients need an ambulance for medical reasons then the ward will arrange this and tell you that this is happening.



Have a think about how the patient will get home and if you have any questions or concerns please talk to us.



Where to pick up patients?

Most patients will be moved from the ward to the discharge lounge and you can pick them up from there. Some patients might need to be picked up from the ward instead.

We will try to have most patients ready to leave hospital in the morning, however sometimes it can take a bit longer to get everything ready.

Please talk to us the day before discharge and we will tell you where to pick up the patient and what time we think they will be ready to leave.

Remember

Before leaving, patients will need **house keys, clothes, footwear and an outdoor jacket**. Please help us by making sure these items have already been brought in.

