

Reaching Carers

Report on Reaching Carers Project at
Southampton General Hospital
February 2011



This project was funded by the Department of Health's Reaching Out to Carers Innovation Fund

It was led by Citizen Choice CIC and carried out at Southampton General Hospital during February 2011 together with the following organisations:-

Carers Together

Diabetes Aware

Hampshire Neurological Alliance

Romsey and District Carers Forum

Romsey Young Carers Project

Southampton Asian Carers Group

Southampton Seniors Council

Southampton University Hospital Trust (SUHT)

Southern Test Older People's Forum (STOIC)

Established Patient / Carer Group at SUHT

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'Everyone becomes a carer sometime in their life'

Executive Summary

The aim of this project was to identify hidden carers and offer information, support and signposting to anyone carrying out a caring role.

Specifically, this project was set up to:

- work with patient groups and professionals at Southampton General Hospital
- seek out and survey carers of people in condition specific groups in hospital
- provide key carer information to those providing care
- provide GP practices with local carers information and signposting

This project was conceived, scoped and implemented by a group of carers with experience of having the person they care for hospitalised, in conjunction with their supporting organisations, using the coproduction methodology.

During February 2011, 1400 surveys and information packs were handed out to visitors at Southampton General Hospital, with a return rate of 10%.

The information pack included the telephone numbers of support organisations, useful information about questions and issues to consider before the cared-for person leaves hospital and a copy of the Personal Profile (see Related Projects Appendix 3).

The respondents included 31% who performed no accepted caring role. All remaining respondents were carers. Of these, 40% did not identify themselves as carers although they performed a variety of caring activities, which for a significant number of respondents included personal care.

Comments from all respondents included many showing appreciation for the care the person they were visiting was receiving. However, an overwhelming number of comments concerned lack of communication between the medical staff and visitors. Additionally negative comments were received about parking facilities and the cost and quality of food. All comments have been passed to Southampton General Hospital.

Following this activity 10 recommendations were made, the most significant being:-

1. Communication between hospital and visitors needs to be improved.
2. The process for making information and signposting available to all visitors needs to be improved.
3. Hospitals need to recognise the role of carers in the long term recovery of the patient.
4. Carers need to be supported to understand when they are carers or when they undertake a caring role.

'The name doesn't matter – it is the action that counts'

1. Introduction

Carers support organisations, like Carers Together, have been aware for many years that there are a significant number of carers in the community who are not known to statutory and voluntary organisations. This may be their choice but often means they are not aware that they are carers.

Relatives of people with long term health conditions can be reluctant to call themselves carers. This may be because the person they care-for manages and undertakes their own care e.g. a person with diabetes. It may be because the carer sees the caring role as part of their relationship with the person. For example, a wife or husband caring for their partner will feel it is their “duty” or “job” to look after their partner, and will not see it as being a carer or as performing a caring role.

This situation may continue until a crisis occurs such as a medical emergency, or the condition of the cared-for person deteriorating to such an extent that the position becomes untenable. In these situations, practical support and the benefit of experience from other carers is invaluable and can avert or reduce the severity of any resultant crisis.

In this document, people who provide care but don't recognise themselves as carers are referred to as hidden carers.

It is estimated that **1 in 5** of us will become carers in our lifetime. Depending on how an individual comes into the caring role, there are support organisations nationally and locally that can offer them support and signposting.

Without this support, many carers may find their caring role becomes unmanageable and by the time they contact support organisations they are in crisis. This results in significant distress to both the carer and the person being cared for and often incurs extra costs. For example:-

- Carer breakdown or illness resulting in the need for professional support
- The need for an emergency call to Adult Services, hospitalisation, a statutory care package or admission to a care home
- Mental health, stress, physical strain on the carer and the cared-for person
- Relationship breakdown
- A move from coping to not coping
- A move to critical or substantial needs
- Short term or long term change that could mean the need for more funding and resources or the need to reduce pressure

In an attempt to understand further how this happens and to find ways to prevent this escalation, Citizen Choice, in partnership with other organisations, initiated a short project, funded by the Department of Health, at Southampton General Hospital.

The Project aimed to:-

- work with patient groups and professionals at Southampton General Hospital
- seek out and survey carers of people in condition specific groups in hospital
- provide key carer information to those providing care
- provide GP practices with local carers information and signposting

It was decided that the most appropriate method of achieving this result would be to visit the hospital during visiting time and hand out both a survey and an information pack to as many visitors as possible.

In addition, information packs and surveys would be sent to each GP Surgery in Hampshire for them to pass on to any relatives of patients, who had recently come out of hospital.

2. Approach

This project was conceived and implemented using the coproduction methodology by a group of carers in conjunction with their supporting organisations. Many of the carers had extensive experience of having the person they care for being treated in hospital, as well as being the patient themselves.

In keeping with the requirements of the coproduction methodology, everyone in the team had an equal voice, and everyone was given the opportunity to be involved at every stage of the process, from design of the service to completion.

Representatives from the organisations running and supporting the project as well as carers with experience of having the person they care for hospitalised, were brought together for an initial meeting at the Hampshire Carers Centre. The aims of that meeting were to:-

- Confirm agreement with the objectives of the project
- Decide how the project was to be run
- Design the survey
- Agree contents of the information pack

It was agreed that the surveys and information packs would be:-

- Designed by the coproduction team of volunteers and staff from the supporting organisations
- Produced by Citizen Choice.
- Handed out by volunteers, supported by staff members of the supporting organisations, at Southampton General Hospital during each visiting session in February 2011

It was also agreed that:-

- Volunteers and staff would be offered a training session before the survey started
- Results would be collected and analysed by Citizen Choice
- Citizen Choice would produce the "Reaching Carers Report"
- After the end of February one or more debriefing meetings would be carried out to ensure all feedback had been collected and all lessons learnt from the project were documented. The initial finding of the project would also be presented at this meeting.
- Citizen Choice would send out the information packs to the GPs in Hampshire, Portsmouth and Southampton

3. Information Pack Contents

The information pack contained the following:-

Introductory Letter	This explained the purpose of the survey and requested that the visitor complete the survey.
Survey	A great deal of time was spent making sure the survey was asking the right questions and that the questions would be understandable to all. There was agreement that the survey should be no more than 2 sides of A4, so the design in Appendix 1 was conceived.
Personal Profile (PP)	<p>The Personal Profile is a form which has been developed by the Common Assessment Framework for Adults project. The form has been designed to help everyone who uses or may need to use health or social care services. It helps an individual to document information about him/herself which health and social care professionals repeatedly ask for, thus saving the time of the service user, the carer and the professional.</p> <p>The personal profile is useful at all times, but more especially when an individual is in hospital. Forms are available to download free of charge from www.sayitonce.info.</p>
PP Leaflet	The Personal Profile leaflet contains useful information about the Personal Profile and is available to download from www.sayitonce.info .
Do you care Leaflet	This is a leaflet produced by Carers Together and which gives useful information for carers. The leaflet is available from Carers Together on 01794 519495 or by emailing admin@carerstgether.org.uk
Information Leaflet	<p>The information sheet, which was titled "Information you may find useful February 2011" included contact details of organisations, national and local, chosen so that they would be useful to as many carers as possible.</p> <p>Additionally, many organisations were included because they perform a significant amount of signposting. This leaflet is in the information pack.</p>
Leaving Hospital	This checklist for patients and carers included information which many carers find useful to think about before the person they care for leaves hospital.

4. Delivery

The managers of Southampton University Hospital Trust generously agreed to the project being carried out at Southampton General Hospital and provided a room for the staff and volunteers to use and support to allow the project to take place.

Thanks especially are due to the staff at Voluntary Services and the ward staff who communicated information about the project to their patients' visitors.

During visiting times throughout February 2011, volunteers, many of them carers, as well as staff from the supporting organisations, handed out the information packs and surveys to visitors at Southampton General Hospital.

- Each visiting session was covered by between two and six volunteers.
- On arrival at the hospital each volunteer would sign in at the Reaching Carers office and collect their pack, Citizen Choice identity badge and Hospital Volunteer identity badge.
- Generally volunteers worked in twos or threes and decided together which areas they would cover at the start of their shift. They would use the comments in the signing in book, to see where previous teams had been and how successful previous volunteers had been at handing out packs in each location.
- Volunteers would generally meet back at the Reaching Carers office part way through the shift to have refreshments, replenish their packs, and meet any new volunteers who had agreed to start volunteering slightly later.
- At the end of the shift volunteers returned to the Reaching Carers office to sign out, return their badges, return/replenish their packs ready for the next day and leave any completed surveys for collection by Citizen Choice staff.
- Completed surveys were collected from the hospital and analysed by Citizen Choice.
- Facilities were available for carers to collect additional paperwork from the office and to send completed surveys by post

5. Project Review

At the end of the project period, everyone involved was given the opportunity to input their comments on the Reaching Carers activity and to provide suggestions on how well the project worked and how it could have been improved.

This has produced a replicable process that could be used at any hospital in the country.

5.1 What we did well

- Worked in coproduction to produce the survey questions and the contents of the information pack
- Kept the survey to one sheet of paper (A4 folded), which was printed on coloured paper to make it easy to identify
- Provided a pack of useful information for each visitor
- Only included information in the pack which would have been useful to the maximum number of visitors e.g. the information sheet contained a list of useful telephone numbers for national and local organisations. These were chosen carefully to ensure they were organisations that could provide the most benefit to anyone seeking help and would signpost to other support when appropriate
- Gave the visitors the survey separately from the pack. This ensured they were aware that we weren't asking them to complete the whole of the pack, just a one page survey
- Made additional material available to the volunteers to hand out where they felt it was appropriate. This included:
 - the hospitals complaints procedure
 - the guide to residential care
 - the guide to better care and support
 - a leaflet about young carers

Although only a small quantity of additional material was handed out, the visitors who received them were very grateful

- Provided the volunteers with a canvas bag to hold additional material and additional copies of the packs and surveys. Practically this made the exercise easier
- Had a training session where all the volunteers could meet and become familiar with the survey questions, the pack and processes
- Had a dedicated room available for the volunteers at the hospital where they could meet and leave any personal possessions, heavy bags etc.
- Displayed the volunteer rota on the notice board in the dedicated hospital room. This showed volunteers who they would be working with and allowed for sharing of travel arrangements
- Provided free tea and coffee for the volunteers
- Provided volunteers with free parking (courtesy of SUHT)

- Used a signing in book so we knew how long each volunteer spent handing out packs and how many they had handed out
- Had a contact sheet so that staff and visitors could leave messages for each other
- Had a member of staff present all the time during the first week to support volunteers in what they were doing and ensure consistency and continuity. This support was made available throughout the project but was not always on site
- Ran the project over half term. This meant that we could reach more carers with children, when they brought their family into visit
- Talked to visitors
 - when they were waiting for a lift – they were already waiting so we didn't take up any more of their time
 - in the lifts when travelling from floor to floor
 - when they were having a coffee or meal break in one or other of the coffee bars and restaurants and when volunteers were also having a break.
 - coming and going from ward areas
- Had meetings after the event to collect the verbal communication and feedback received by volunteers. This was sometimes different to the feedback on the surveys and added an extra component to the project

5.2 What we would do better or differently next time

- Publicise the project activity before the start date. This was impossible because of the tight time scales attached to this project, but given additional time this is an area which may have improved the numbers of surveys returned
- Ensure all staff at the hospital were aware of the activity. This would have been a priority if timescales had allowed
- Investigate other ways for visitors to complete the survey, e.g. on line
- Emotionally prepare volunteers. Some of the volunteers had been to the hospital previously with their loved ones or as patients and had not always had a good outcome. This meant that some volunteers felt intimidated by the thought of going back into the hospital. Once they had completed their first shift they were fine, but if these feelings had been anticipated and covered at the training session, they would have been dealt with better
- Ensure volunteers were aware in advance of how tiring it can be handing out packs and chatting to visitors, and to ensure they didn't over-extend themselves with the number of hours they volunteered
- Include a role play session within the training session, to help volunteers talk to their first few visitors. Initially some volunteers were worried about approaching visitors, and so didn't hand out many packs during their first shift. If they had been given an opportunity to practice this beforehand, sharing some of the very professional techniques of some of the volunteers and staff, the exercise would have gained momentum faster

- Have a booth or table with a large sign. This would have allowed some of the volunteers to sit down for a rest and to sit with visitors who needed help to complete their survey or, crucially, wanted to talk and offload
- Change the times the survey was carried out. We covered visiting time – from 3pm until 8pm, but if we repeated this exercise we would:
 - Start at 2:30pm. This would mean we would be speaking to visitors when they had more time. Especially at 3pm, many visitors were rushing to meet their relative
 - Finish before the end of visiting time. Between 7 and 8 was normally very slow, with only 1 or 2 surveys being handed out
- Modify the question about who was being visited, by expanding the “relative” option to include partner, parent and son/daughter
- Consider adding additional questions to give more information about the person being visited. The questions would need to be chosen carefully, because, by adding questions, the size of the questionnaire would be increasing. This could make some visitors less likely to complete the survey. The following additional questions could be considered:-
 - How old is the person you are visiting today?
 - under 18
 - between 18 and 65
 - over 65
 - Does the person you are visiting live:

<ul style="list-style-type: none"> • Independently • with a carer • other 	<ul style="list-style-type: none"> ▪ in a care facility ▪ with you
--	--
 - Does the person you are visiting have a pet?

<ul style="list-style-type: none"> • No • Dog • Other 	<ul style="list-style-type: none"> ▪ cat ▪ bird
--	---
 - If you provide meals for the person you are visiting, how many meals would you provide in the average week?
 - If you provide transport for the person you are visiting, why is the transport required (e.g. regular shopping, hospital and doctor’s appointments, leisure activities)?
 - If you arrange care and other support services in the home, which services do you use? Please specify which.
 - If other cost effective services were available, which additional services would you choose to arrange?
 - Activities question – for each of the specified activities, on average, how much time each month was spent on each activity?
 - Are you aware of any carers networks in your area?
 - If you are not currently linked into a carers network, what services could they provide which would encourage you to engage with them and use their services?

6. Results

During February 2011, 1400 surveys and information packs were handed out to visitors at Southampton General Hospital, with a return rate of 10%.

During the 28 days:-

- 29 volunteers and staff assisted with the project
- 28 4 hours visiting sessions were covered
- 205 volunteer and staff hours were spent working on this project
- 1400 surveys and information packs were handed out to visitors
- 1400 Personal Profiles were handed out to visitors
- 320 Packs have been sent to GPs in Hampshire
- 142 surveys returned

Just under 18% of surveys included contact information.

- 41% respondents identified themselves as carers
- 27% respondents did not identify themselves as carers but performed 1 or more care tasks
- 31% respondents were not carers

This means that of all carers, 40% do not identify themselves as carers.

6.1 Who was Being Visited?

Carers

- 84% of carers were visiting a relative

Hidden Carers

- 84% of hidden carers were visiting a relative
- 11% of hidden carers were visiting a friend
- 5% of hidden carers were visiting a neighbour.

Not Carers

- 70% of people who performed no caring role were visiting a relative
- 13% of people who performed no caring role were visiting a friend
- 3% of people who performed no caring role were visiting a neighbour
- 18% of people who performed no caring role were visiting somebody who was not a relative, a friend or a neighbour.
- 3% of people were visiting more than one person

6.2 Additional information about Carers

- 4.6 the average number of years carers have been caring
- 14% are linked to a Carers Network or support group
- 57% are known to their GP as a carer
- 43% are on the medical notes of the person they care for as a carer
- 24% have a Lasting Power of Attorney (Health & Welfare) for the cared-for person.

6.3 What services do carers provide?

The section looked at the type of care provided by carers and contrasts it with the type of care provided by hidden carers.

Carers	Hidden Carers	Services
74%	26%	provide personal care
78%	47%	cook meals
66%	26%	provide gardening
33%	16%	provide pet care
91%	91%	shop
78%	61%	provide transport
83%	47%	provide laundry services
59%	45%	befriend
59%	32%	arrange care and support in the home
7%	5%	provide "other" services

On average, "Carers" provide 6 of the above activities to the person they care for; "Hidden" carers provide 4 of the above activities to the person they care for.

Comments

1. Most carers do not consider that they provide "services". They believe they have a role in supporting their relative or friend and this is part of their "relationship".
2. Many of the tasks undertaken by carers, such as shopping are seen as normal activities rather than something specific they are doing for the cared-for person.
3. The number of hidden carers performing personal care was higher than expected. This is one area where it was thought that a carer, if performing this activity would recognise the activity as caring. However, this lack of recognition could be due to the fact that carers come into their role gradually, and may for example start with helping to do up the buttons on a shirt and drift, without the carer noticing, into washing and/or dressing the person they are caring for.

4. The cooking meals activity was high for both carers and hidden carers. It would have been interesting to have asked how many meals a week are cooked e.g. some carers may be cooking one meal a week; others may be preparing all meals.
5. The figure for gardening for hidden carers was low. This figure could have been put into more perspective if we had asked the age of the person being cared for and if they were living independently. For example, dependent children wouldn't have the responsibility of caring for their garden, which would be the same for any person living with their carer – the responsibility of this task would be seen to be with the carer and so the “cared for” could have been excluded from this figure.
6. The figure for Pet Care was low. If we had asked about the type of pet, this may have provided additional information for other organisations e.g. Cinnamon Trust.
7. The figure for shopping was high and coincidentally the same for carers and hidden carers. This figure could have been given more weight if we had found out if the person being cared for was living independently, but may indicate that shopping is one of the first activities people require help with. More research is required in this area because as this is such a high figure, if this activity does prove to be a problem, intervention here could help a great number of people.
8. The transport figure is lower than the shopping figure, and logically these figures could be related. However, this figure could be lower because of the provision of community transport in the community. If the survey was repeated it would be interesting to find out what the transport was, e.g. was it for a regular shopping trip, hospital and doctor's appointments or for days out and other leisure activities.
9. Laundry services again would have benefited from knowing which of the cared-for people lived independently, and which of the cared-for lived with their carer. However, there was a significant difference between the figures for carers and hidden carers.
10. Befriending was lower than expected for both carers and hidden carers. However, this could have been because a significant number of the people being cared for were partners of the carer/hidden carer. When caring for a friend or neighbour, a carer may perceive they are befriending the person being cared for. When providing care to their partner, elderly parent or other relative, befriending just wouldn't come into it – it is perceived as part of their standard relationship.
11. Arranging care and other support services in the home, at 59% and 32% for carers and hidden carers respectively, was encouraging because it is showing that carers and hidden carers are not all trying to do everything themselves. However, if this activity was repeated it would be useful to find out what care or support services were being provided. An additional question to be asked would be what services would be procured if they were available or available at a cost effective level.
12. The “provide other services” activity was low but did include significant activities such as medical care. Although people completing this activity were asked to specify these activities, because many of the activities performed by carers aren't seen as caring but as ‘business as usual’, it is sometimes difficult for people to think about what they do as a caring activity.
13. If we repeated the survey it would have been advantageous to ask how much time each month was spent on each activity.

6.4 Leaving Hospital

This section looked at what happens when the patient leaves hospital and how involved carers and hidden carers were in the arrangements made for discharge.

Carers	Hidden Carers	
50%	26%	felt they were being fully included in patients discharge plan
52%	26%	felt they were being fully included in patients Care Package.
79%	63%	wished to be included in the plans for patients discharge
47%	34%	know how to get support when the patient leaves hospital
28%	24%	know what to do when their needs are not being taken account of

Comments

1. Most patients don't think about leaving hospital until they are told they can go home. At this time the patient may be so anxious to return home that they do not consider the realities of returning home. This means that they may not push to ensure the correct facilities are in place to ensure their safety and enable them to cope.
2. Significantly more carers wish to be involved in the plans for the patient discharge than are actually included. It cannot be good practice to exclude, from the discussions involving the discharge, the people who are most likely to make the discharge arrangements work.
3. The 34% of hidden carers who know how to arrange support once the patient leaves hospital is very similar to the 32% of hidden carers who currently arrange for support for the person they care for. However, the number of hidden carers who arrange care and know where to go to for support is only 15%.

6.5 Information

This section looks at how much carers know about the support that is available to them once the patient leaves hospital.

Carers	Hidden Carers	
45%	32%	Benefits and other financial information
31%	34%	Local community facilities
29%	24%	Local support groups
67%	58%	The health condition of the patient
79%	87%	Is the visitor comfortable to ask for more information

Comments

1. The results in this section show a significant requirement to increase information available to all carers.
2. The figure of carers comfortable to ask for more information is high, but the problem is that unless the carer knows what is available, they don't know who or what to ask.
3. Some carers are frightened to ask questions.
4. Some visitors are unable to ask questions because they are unable to find the appropriate medical staff to speak to during visiting times.
5. Some visitors feel unable to ask questions because they believe staff are already too busy. This acts as a barrier, preventing communication.

6.6 Useful Information

This section looked at how useful carers found the information pack which had been given to them with the survey.

Carer	Hidden Carer	
78%	87%	Leaving Hospital. A checklist for patients and carers
66%	68%	Personal Profile
74%	84%	Information you may find useful February 2011

Comments

1. This section shows that the type of information provided to visitors during this project was useful to the visitors.
2. If the visitors receiving the information found it useful, it should be available to all visitors.

6.7 Additional Information

Many comments were received, including numerous praising the hospital staff. These have been documented in Appendix 2.

However, the overwhelming theme of the comments given both in writing and verbally to the volunteers was a frustration with the lack of communication between the medical staff and visitor. Doctors were not available during visiting hours and sometimes patients had been moved or discharged and visitors had been unable to find them causing great distress.

Other items raised include:-

- Parking, both the cost and the availability of spaces
- Quality and range of food available for patients
- Quality and cost of the food in the canteen.

6.8 GP Feedback

The information packs were sent out to all GP surgeries in Hampshire, Portsmouth and Southampton during March 2011. This was to inform them of the survey and to enable them to discuss it with any carers of patients who had recently been in hospital.

In addition to the standard packs issued to visitors at the hospital, the GP packs included a:-

- “Do you Care?” poster, provided by Carers Together, which is designed to be displayed in the surgery to encourage carers to register with their GP as a carer.
- Registration form, again provided by Carers Together, which many Hampshire GPs are now using as a template when they register carers.

This report will also be made available to GPs in due course.

7. Recommendations from the project

1. Improve communication with all visitors.

This exercise has shown that there is a significant amount of dissatisfaction with the quality of communication between medical and nursing staff and visitors.

Recommended Action: The Hospital to improve access to, and/or availability of, staff during visiting times and improve opportunities for visitors to talk to clinical and nursing staff when visiting their relative or friend

Recommended Action: The Hospital to support nursing and clinical staff in communicating better with relatives

2. Improve the process for making information and signposting available to all visitors.

This exercise has shown that a small amount of relevant information is helpful to carers and improves their ability to cope both whilst the person they care for is in hospital and to plan for them going home.

Different formats and ways of providing the support and information should be explored.

This may be better undertaken in coproduction with carers, health, social care and voluntary sector organisations.

Recommended Action: The Hospital to investigate how to improve the process for making information available to all visitors by working together with carer-led organisations to offer information and signposting, especially when a cared-for person is in hospital

3. Hospital staff need to recognise the role and expertise of carers in the long term recovery of the patient.

Family and carers need to be included in all aspects of the patient care and receive communication throughout the hospital stay. Successful discharge is often dependent on the carer being involved in all the plans.

Recommended Action: The Hospital to support the development of a carer-led facility at the hospital to reach carers and support them to become more involved.

4. Carers need to understand they are carers. This is a long term aim but could be helped by

- a. Supporting people to understand what constitutes the caring role.
- b. Carers being identified by GPs and other health workers
- c. Carers being identified by social workers and other social care workers.
- d. Carers being identified by workers in children's services.
- e. Carers being identified by the voluntary sector.

5. More carers need to be linked to carer-led carers networks.

This could help them to access information and support when and how they need it. The response from many carers approached at the Hospital was to offload their concerns and worries. This indicated a need for a more regular presence at the hospital where visitors can go for independent support and information.

Recommended Action: All visitors who included their contact details on the survey to be sent the results from the survey and given information about their local carers network.

6. Comments on parking, visitor food and patient food.

Recommended Action: Citizen Choice to contact the Hospital with the comments about parking and food at the Hospital.

7. The process used in this survey could be replicated in any hospital. This may be useful in identifying common issues as well as specific localised concerns.

Recommended Action: The process of the project with the adjustments made in the light of actual experience should be produced as a template.

8. Coproduction methodology should be adopted as the method of choice to deal with the need for better communication

9. The technology needed to implement some of the above recommendations should be investigated and where sharing of information is paramount the possibility of linking to the Common Assessment Framework should be investigated.

10. The survey results showed that many people receiving some degree of care, need help with their shopping.

Recommended Action: This area should be investigated because if this activity does prove to be a problem, the benefits of providing aid in this area could be an increase in the number of people who can continue to live independently.

Currently a supermarket shopping home delivery service does exist in most areas but there is minimum order limit. This prevents some people, particularly those who live alone or older couples, from taking advantage of the schemes

Appendix 1
Reaching Carers Survey
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Reaching Carers Survey

We are conducting this survey, in conjunction with Southampton General Hospital (SUHT), to help us to find ways to reach relatives and friends (i.e. unpaid carers) before they are in crisis. We aim to find out what information and support carers need to help them to support their relative or friend.

If you are visiting somebody in the hospital it would greatly help us if you could complete and return this brief questionnaire to the volunteers who gave it to you, or by sending it to the address at the end of the form.

Your help would be much appreciated and will help us, and the hospital, to provide better information and support to patients and relatives.

*Citizen Choice Survey for the Department of Health
January to March 2011*

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Location/Area/Ward			
Date			
About You			
Are you visiting somebody in this hospital today?	Y / N		
Are you their relative / friend / neighbour / other? <i>(please specify)</i>	Y / N		
Do you consider yourself to be a carer for the person you are visiting or for someone else?	Y / N		
If you answered yes to the above question, how long have you been a carer?			
Are you linked to a carers network or support group?	Y / N		
Do you provide any of the following support to the person you are visiting or someone else?			
Personal care	Y / N	Shopping	Y / N
Cooking meals	Y / N	Transport	Y / N
Gardening	Y / N	Laundry	Y / N
Pet care	Y / N	Befriending	Y / N
Arranging care and support in the home			Y / N
Other (please specify)			

Appendix 1
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If you are a Carer	
Does your GP know you are a carer?	Y / N
Are you on the medical notes of the person you care for as being their carer?	Y / N
Do you have a Lasting Power of Attorney (Health & Welfare) for the person you care for?	Y / N
Leaving Hospital	
Do you feel you are being fully included in the patient's:	
Discharge Plan	Y / N
Care Package	Y / N
Do you wish to be included in the plans for the patient's discharge?	Y / N
Do you know how to get support when the patient leaves hospital?	Y / N
If your wishes or needs aren't being taken into account, do you know what you can do?	Y / N
Information	
Do you know about:-	
Benefits and other financial information	Y / N
Local Community facilities	Y / N
Local support groups	Y / N
Have you been given information about the health condition of the person you care for?	Y / N
Would you feel comfortable to ask for more information?	Y / N
Could you please tell us what health condition(s) they have?	

Appendix 1
Reaching Carers Survey
Page 4

We have included some information with this survey – do you think it will be helpful to you?	
Leaving Hospital Information for patients and carers	Y / N
Personal Profile and leaflet	Y / N
Information you may find useful	Y / N
What additional information would have assisted you during the stay in hospital of the person you are visiting?	
What constructive comments do you have on any aspect of their stay in hospital?	
Contact Details	
You may complete this questionnaire totally anonymously. However, if you would like feedback on the survey or any other information and support, please complete your details below.	
Name:	
Address:	
Telephone:	
Email:	
I would be interested in receiving more information about:-	
Please return this form to the Survey Volunteers at the hospital or post to: Citizen Choice 9 Love Lane Romsey SO51 8DE	

Appendix 2
Additional Comments Received
Page 1

1. “What additional information would have assisted you during the stay in hospital of the person you are visiting?”

Compliments

- The staff have been amazing
- Good info provided.

Communication

- Just being informed about progress. Being told what might happen would have prevented some nasty shocks.
- Reasons for delays – inactivity perceived (whole day “nil by mouth” Prep for scan” not done until following day).
- How rehab was going on. What patient was eating on daily basis
- More easily available information about my mother’s operation and hopes for the outcome. Plus an idea of what will happen on her discharge from hospital.
- Routine updates on their progress. I feel I am pestering when I search out people to ask.
- Being told where my father was.
- Transfer to adults – more information in childrens’, e.g. didn’t know about learning team pre transfer.
- There seems to be a lack of communication between departments. Relatives do not get enough information on admission.
- Knowing who was in charge of the ward.
- Easier access to speak to doctor(s). They do not seem to be available during visiting hours or weekends.
- More frequent updates on the progress of the patient.
- To have been able to speak to a doctor instead of a nurse who didn’t seem to know anything.
- Information early on if it looks as if time will have to be spent in a care home after hospital and what their/your rights are.
- More information as to patient’s condition and prognosis.
- Being kept updated on what was happening.
- Being told what was wrong with my wife day to day by doctors/ senior nurses.
- More communication with doctors about the health and progress of my mum and the length of stay in hospital.
- More feedback from the doctors.

Appendix 2
Additional Comments Received
Page 2

- More contact with doctors. Information given to patients but unable to retain to pass onto family.
- More knowledge of where to obtain follow up assistance to the home.
- More info on transfer to Dorchester hospital
- Somebody to speak to
- Information regarding my mother's illness.
- Direct information to me by the nursing and medical staff re patient's condition and discharge plans.
- More access to surgeon or somebody who had up to date information on my mother.
- More feedback from doctors.
- Nurses knowing what's going on.
- Good communication needed.
- Progress information
- Would like to be kept up to date on progress of care.
- Factsheet about childhood AML explaining what is & isn't o.k. as it would help us to think relatively about support that is allowed.
- More on medical aspects and on benefits/services/future needs.
- When he was first admitted and his condition was more serious it was difficult to get up to date info on his condition.
- A daily update on patients progress from the doctor, although nurses have been excellent.
- Better communication when speaking to so called professionals.
- It's the first time anyone has offered me any information since my mother was admitted two months ago.

Parking

- Parking charges info and realistic time scale of stay.
- Easier parking due to disability at present.
- Free parking

Miscellaneous

- A patient telephone (not linked to TV rental)
- The personal profile form states "please return this form to me" – who is me? I will look on the web site.
- To be offered a personal profile form to complete on behalf of my father.
- The amount of time I had to wait for patient to receive discharge papers. This obviously raises revenue for the hospital via parking and restaurant.
- Cleaner toilets and better signing to more toilets

Appendix 2
Additional Comments Received
Page 3

2 “What constructive comments do you have on any aspect of their stay in hospital?”

Compliments

- From what I've seen the staff have been fantastic.
- I was impressed with helpfulness of nurses/staff on G7 ward.
- C6 should keep up the good work.
- The staff are GREAT.
- Excellent care
- Professionalism of staff
- The care has been excellent overall.
- Everyone kind and helpful but stretched to full capacity.
- Excellent care given in Neuro ICU by all the staff.
- Staff lovely and easy to talk to.
- Felt she was in good hands.
- Very grateful for all the wonderful care and help.
- So far, we have been impressed with the care and communication!
- Care has been excellent and all staff have been helpful.
- Very pleased, feel that my uncle is being well cared for.
- Nursing staff fantastic – helpful and sympathetic & caring
- Excellent Care
- Very good care
- Friendly and helpful ward staff who explained everything.
- Nurses are respectful to Dad and helpful. I am generally happy with his care.
- All seems v. busy and well organised.
- The hospital is very clean and they were well looked after during their stay
- Good level of care provided
- Ward seemed well organised

Communication

- Lack of information
- Everyone seems so busy rushing around, they do not seem to get time to speak to their patients.

Appendix 2
Additional Comments Received
Page 4

- Assumptions were made about the level of response of my mother but pain levels had not been reduced. Staff need to listen to relatives as they may have relevant input.
- It does seem to take forever to get anything sorted out when you have requested help. I do realise they are all very busy.
- That doctors and senior staff make themselves available at visiting times.
- Doctors need to provide more communication with carers and family so they stay informed.
- Better liaison with ambulance service to facilitate quicker service
- My father has dementia so cannot provide his own info on medical history, abilities, requirements etc. My initial offers to provide this info were dismissed. Someone at the hospital should make an appointment (not phone call) to discuss all relevant matters with carers.
- You might like to devise a leaflet for outpatients people.
- Easier contact with me by a liaison officer, as to what assistance can be given and by whom.
- Lack of signage when you leave hospital – how to get to motorways.
- A daily update on patients progress from the doctor, although nurses have been excellent.
- The patient I was visiting was NBM – was given permission for food by the doc – then the physiotherapists advised against so please – better communication between professionals. The contradictory advice was upsetting to patients and relatives.
- Deaf people find it very hard to access BSL sign language interpreters. Could your hospital not have one or two on their books?
- The information in this package has shown what help I could have received.
- Lack of communication between staff and patients.
- Too many people asking the same questions and receiving the same answers.
- Not enough aftercare.
- Not enough info on his deteriorating condition.
- Better information and continuity of care

Food

- Assistance with some foods and drinks
- Food could be more appetising, e.g. there is no butter on sandwiches.
- The food in the canteen very expensive. Carers should be allowed staff rates.

Appendix 2
Additional Comments Received
Page 5

- On G7 I had to ask for a drinking straw so my mother could drink without spilling water. A small thing but important.
- The menu did not contain anything suitable for very poorly patients, i.e. plain poached veg.
- Since the changes in catering, since patient's previous admissions in November 2009 the food is VERY POOR, unappetising and over-cooked and re-heated.
- Food poor
- Smaller quantities of food for elderly – tempting snacks for poorer appetites.
- Patient unable to order meals without assistance, confused when asked by hospital staff. Family would have appreciated form on previous day. Requested menu but not available.
- More opportunity to speak with specialist. To include the carer, not just the patient.

Parking

- Cheaper parking
- Parking is too expensive and parking spaces not sufficient.
- Very expensive to use the car parks.
- Parking needs to be improved.

Cleanliness

- Cleanliness
- A & E was dirty.
- Ward seemed clean

Miscellaneous

- Noisy dinner trollies.
- Lack of chairs for visitors.
- Didn't get the care he should of, was just told to stay in bed cus there is a shortage of nurses.
- Less moves from ward to ward (10 moves in 5 weeks). Some were necessary due to contracting c difficile.
- Was moved from ward to ward several times in a short stay, which meant getting to know people again.
- None at times. Very disappointing
- More entertainment at bed side.
- Lego treats are excellent X Box is really great too.
- Lack of care and understanding to relatives.

Appendix 2
Additional Comments Received
Page 6

3 Comments received and made by volunteers at the post event debrief

Complements

- The staff are kind and the care is wonderful.
- Good comments about the care, mostly in Neuro.

Pack

- Information very helpful, can I have another pack.
- An elderly brother and sister had been visiting a relative since December and this was the first time anyone had offered anything to them which would help them.
- Pack was really useful.
- Wish I had had this pack last time my father was in hospital
- This information will be really helpful on discharge.
- This info will be really useful to us.
- Can I have another Personal Profile for my sister?

Communication

- Nurses don't seem to know anything about what help is available to the patient and family outside of hospital.
- Staff are too busy to explain what they are doing, even to the patient. This was the comment of a Carer of a patient with dementia who was in for medical reasons.
- I find it all rather confusing but I don't like to bother the poor nurses.
- A chap whose mum now needed a care home was delighted that we could supply the guide to residential care and explain it to him. We also had a chat about how to arrange visits and what to look for when checking the homes. His comment was 'How wonderful to find someone who can advise us and give us the information we need, right here in the hospital. We didn't have a clue who to go to'.
- A few Nurses unhelpful not knowing what was going on with the patient.
- Senior doctor often unavailable and visitors were palmed off with a junior doctor. Lots of people said all the doctors disappeared at visiting time.
- Went to visit someone and they weren't there.
- "My son is getting really good care but I am not being kept informed. I need to know".

Appendix 2
Additional Comments Received
Page 7

- Tried to visit somebody and they had been discharged.
- Signposting in hospital isn't always that clear and notices are not always clearly placed.
- League of Friends are not always in the right place to direct visitors and are not always there.
- People are often stressed and better signposting is needed to take this into consideration.
- Father has been moved today and don't know where to and don't know how to find out, other than going to the ward where he was.
- Visitors need to know what is happening, even if the answer is "I don't know yet". It means we are not being forgotten.

Parking

- Annoyed at how long it took to get into the car park.
- It's expensive and you can't find a space.
- No indication of where the spaces are once you are let in.
- If you go onto the top floor you can't get back down unless you go round the one way parking system again.

Food

- Comments about the food – not always good.
- Food often expensive in the canteen and food for patients not appropriate or simple enough.
- Some patients found it difficult to complete the daily menu.

Cleanliness

- Cleanliness not always good.

Miscellaneous

- Some people commented they would complete the survey later.
- Several people asked about the option to complete the survey via the internet.

You must be the change you wish to see in the world.

Mahatma Gandhi

**Reaching Carers Project at Southampton General Hospital
January to March 2011**

Report prepared by Citizen Choice on behalf of the partners

Issued June 2011

A toolkit of information included in the survey is available from Citizen Choice. Although it contains local information it can be adapted for use in other hospitals and provides a potential process for replication and coproduction

For a copy of the report or toolkit please go to:

Report prepared by Citizen Choice on behalf of the partners

Issued June 2011

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Reaching Carers 2011

