



The National Carer Organisations, May 2014

Carers experience of hospital admission and discharge

Carers need to plan for taking the person they care for home yet some hospitals give little warning. The carer is central to the success of keeping the person they care for being readmitted (NCO Survey for the Carers Bill)

Spending time in hospital, either due to an emergency or a planned admission is often a time of concern and additional stress for both carers and the people they care for. This is consistently the case, both when it is the carer who is admitted to hospital and when it is the person they care for.

An admission to hospital often results in a person becoming a carer for the first time, or it can signify that their caring role is in transition as the condition of the person they care for deteriorates and there is an increase in their care needs.

Where a carer requires hospital treatment this frequently means they are unable to continue to provide care while they recover, or sometimes, due to ongoing ill-health they may no longer be able to continue their caring role or may have to re-evaluate the level of care they can provide

It is therefore essential that at these times carers have access to information and support, from the point of admission to discharge and that their views are fully taken into account when the discharge plan is put in place

Carer support should be a part of hospital discharge planning and it should be available on discharge where appropriate (Carer, North Lanarkshire)

This is vital to ensure that unprepared discharge does not result in a crisis situation (NCO Survey for the Carers Bill)

Carers' experience of Hospital Discharge Procedures

A recent survey undertaken by Carers Scotland and MECOPP in relation to the Carers Rights Charter asked carers about their experiences when the person they cared for was in hospital. On both admission and discharge, dissatisfaction was high. At these key points, where carers' knowledge and experience of the person they care for is vital, very few carers feel they are treated as key partners. 39% said their experience was poor or very poor on admission and 45% at hospital discharge.

I would pass on my observations / opinions to the district nurses attending my parents. This was either ignored or viewed as an irritation. Case in point; I expressed concern over the increasing discolouration of my mother's toes over many weeks. The nurses insisted there was no cause for concern. I insisted on calling a doctor - against the advice of the nurses. This resulted in my mother being admitted to a vascular ward in ERI, having two angioplasty procedures & three toes amputated. She was never discharged from hospital as she died four weeks after admission. (Carer, Carers Rights Charter Survey)

My biggest problems have been at time of hospital discharge over the past three years which have caused quite a bit of unnecessary stress following long periods of hospitalisation. A lot of it was due to poor communication and lack of attention to detail. I would say that in 5 out of 6 discharges I was definitely not an equal partner and once I was made to feel that I was a nuisance! I was really upset at the time but was too tired to go through the complaints procedure and so let it pass although I know I should have taken action. . (Carer, Carers Rights Charter Survey)

Often when people are anxious to leave hospital they do not consider the additional support they will need when they are at home and the impact this will have on their primary carer and other family members. Taking the carer's views into account is key to ensuring that appropriate support is put in place, avoiding the risk of additional stress and carer strain.

Nobody listens to the carer's advice when hospitals, rightly or wrongly, decide whether or not to send the cared for person home. This has to change (Carer, North Lanarkshire)

Poor discharge planning may also result in the person being re-admitted to hospital. The State of Caring Survey by Carers UK found that 37% of carers said that the person they care for was discharged from hospital too early because either support was not available or they were not ready to come home and 18% of carers surveyed reported that the person they care for had to go back into hospital within one month of being discharged because their health had deteriorated again and 8% within two months.

My mum was discharged from hospital medical ward because she had onset dementia. I had my concerns about her going home to live alone and the hospital Social Work Department were unsympathetic. 4 weeks later my mum was re-admitted to hospital and is going through all of the same process as before. I have great concerns about her being discharged home again and I feel bullied by Social Work. (NCO Survey for the Carers Bill)

Where the care provided by an unpaid carer is included within a hospital discharge plan, they should be able to specify how much care they are willing and able to provide. There should not be a presumption that family members will be available to step in and provide care on an ongoing basis. Planning needs to take account of the complexities of people's lives, such as their employment status, other responsibilities such as dependents and additional caring roles, their age and their own health and wellbeing. Unless carers are fully involved in discharge planning a full picture of what resources are required will not be achieved

I feel the carer should be consulted more. My father said he was ready to go home so he was discharged..I had to take 2 weeks off work to care for him full time. ¹

I work full time as well as taking care of my husband who has MS. When he recently left hospital, I was not asked about the impact this would have on us, what help we had in place or if he would be able to manage in our home. He had to sleep on the sofa for 3 weeks following his release and had many bathroom accidents as both the bedroom and bathroom is upstairs and he can not reach them. Very stressful for both of us²

Experience of carers from BME communities

Where carers are from black or ethnic minority (BME) communities they may require additional support to ensure they are fully involved in hospital admission and discharge procedures and any additional support needs are identified and addressed. This may include

- Language and communication support, particularly in relation to understanding diagnosis, prognosis and ongoing treatment;
- Overcoming cultural barriers which may inhibit patients and families from asking for clarification or support;

¹ State of Caring Survey, Carers UK, 2013

² State of Caring Survey, Carers UK, 2013

- Lack of knowledge about rights and entitlements, particularly in relation to involvement in the discharge process
- Support to organise appropriate care packages prior to discharge

I was so worried about my health condition after the operation. Nobody explain to me what I have to do when I go home. However, because of MECOPP's intervention, the doctor came and explained to me and sorted out my uncertainty. I feel much better after talking to the doctor before the discharge. The bathroom equipment help me a great deal (patient supported through MECOPP)

I feel relief when MECOPP helped me to express my concern that the care package had to be in place before my mother in law went home because I cannot possibly look after her when I work fulltime and have a family to look after. (carer supported by MECOPP)

MECOPP also found that where carers from a BME community were fully involved in admission and discharge procedures, the patients discharge from hospital was more likely to be successful with fewer re-admissions. All but two of the carers and patients supported by their hospital discharge workers were able to return home and remain at home two months after discharge. There have also been no repeat hospital admissions. Of the two who did not return home, one died in hospital and one was admitted into long-term residential care.

When carers are also patients

Where carers are admitted to hospital their discharge plan needs to take into account replacement care to ensure they are not having to provide care which may be physically or emotionally demanding while they are recovering

Hospital discharge planning needs to include replacement care planning to ensure carers do not compromise their own recovery (Carer, West Lothian)

At our consultation events in relation to the proposed Carers Bill, there were several examples provided of carers who were forced to go back to their caring role before they were fit to do so, because there was no replacement care available. One person who had suffered several aneurisms was only able to arrange a few weeks care from an elderly relative in their nineties to support her husband. She then had to resume her caring role as her local authority failed to provide her with any support.

Another carer was advised he should take three weeks off from his caring role, following an operation, but his local authority only provided support for one week.

Research by Carers UK has also found that often carers delay medical treatment, including operations because of concerns about who will replace the care they provide.

I became ill overnight. I was hemorrhaging internally and needed immediate hospital admission. I called social services emergency line. In short it took 10 hours to get adequate help organised before I could get myself to hospital. The consultant said I was lucky not to have died³

Even in cases where carers are able to access replacement care while they recover, this is sometimes taken from their existing short break allocation, with one carer who was in hospital on a drip being told:

you've had your six weeks respite break this year'⁴

Best Practice

There are many best practice examples of projects which have been set up to support carers at times of hospital admission and discharge. Many of these services are provided by local carer support organisations, often in partnership with local Health Boards. They are generally based within hospitals and support carers to:

- have their views taken into account in relation to hospital admission and discharge procedures
- access appropriate information relating to the condition and treatment of the person they care for
- receive support for themselves as a carer
- ensure appropriate supports are put in place at the point of discharge.

It makes our work so much easier after talking to the family with help of the HDSS support worker because we know what exactly the family concerns and preference of for care are and we can start to arrange the care package for the patient. (Nurse in Liberton Hospital Ward 2)⁵

This is done by Inverclyde Carers and it very successful and well used so well worth doing.

However, this support is not available consistently across Scotland and where it is available it is rarely mainstreamed and is generally funded through short term funding sources such as The Change Fund and Carer Information Strategy Funding.

³ Whose Rights Are they Anyway? Carers and the Human Rights Act, Carers UK, 2008

⁴ Whose Rights Are they Anyway? Carers and the Human Rights Act, Carers UK, 2008

⁵ MECOPP ibid

Best practice example: Stirling Carers Centre employs two Carer Support Officers based within the Allied Health Professional team at their local hospital. They work in partnership with NHS professionals to identify hidden carers at all stages of their hospital journey, helping them to navigate their way through the system from admission to discharge. The Carer Support Officers work with carers to enable them to be equal partners in care and therefore play an active role in the discharge planning process. This ensures that the patients and their carers leave hospital with the appropriate support in place to retain as much independence as possible in their communities.

Best practice example: MECOPP employs two Hospital Discharge Support Workers through Change Fund monies to provide dedicated support to BME older carers and those in receipt of care who are admitted to hospital. The purpose of the project is to: identify those who come into contact with acute healthcare services; support them to actively participate in the hospital discharge process; ensure they are referred to appropriate support agencies; and, are supported to remain within the home/community setting. The project works in partnership with a similar initiative provided by the City of Edinburgh Council and NHS Lothian.

A Proposed Duty

Despite the existing Scottish Government Protocol on Hospital Discharge, practice across Scotland differs widely and very often, to the detriment of carers. We strongly advocate that hospital discharge must begin at the point of admission with the full and active involvement of carers. Where necessary, support must be provided to the carer to ensure that their views are taken into consideration.

Discharge planning must take account of the level of care that carers are willing and able to provide and should put in place additional support or replacement care where required.

We therefore propose as an addition to the upcoming Carers Bill, a **Duty on health to inform and involve carers in hospital admission and discharge procedures.**

This proposal is backed by carers with 100% who responded to our survey and at our consultation events supporting the introduction of a duty. Comments included:

Apart from being good practice, it also means that NHS staff are sure that patients are being sent home to a safe and appropriate environment, with those who will take care of their patient, ready and prepared for the role of carer. Would prevent re-admissions, falls, harmful situations and crises (NCO Survey for the Carers Bill)

Carers must be involved as at present too many people are discharged without the correct level of support and end up back in hospital very quickly. (NCO Survey for the Carers Bill)

Contact Details for Further Information

Claire Cairns, Coalition of Carers in Scotland: coalition@carersnet.org

Fiona Collie, Carers Scotland: fiona.collie@carerscotland.org

Suzanne Munday, MECOPP: suzanne@mecopp.org.uk

Heather Noller, Carers Trust Scotland: hnoller@carers.org

The National Carer Organisations are Carers Scotland, The Coalition of Carers in Scotland, Minority Ethnic Carers of Older People Project (MECOPP), Crossroads Caring Scotland, Shared Care Scotland, the Scottish Young Carers Services Alliance and Carers Trust Scotland.