

# Supporting carers through hospital discharge

The role of hospital-based carer support workers

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## Contents

Executive Summary	2
ntroduction	3
Nho we engaged with	4
The hospital carer support worker role	5
mpact of hospital carer support workers	6
Key enablers1	0
Challenges to implementation1	1
Recommendations for implementing a hospital carer support worker approach1	2
References and acknowledgements1	3
Appendices1	4

## **Executive Summary**

Carer involvement in hospital discharge is a key principle of The Carers (Scotland) Act 2016, which provides carers with the right to be involved in planning for discharge when the cared for person is admitted to hospital.

Evidence suggests that carers are not being identified consistently in hospital or involved in hospital discharge planning. Many local teams have implemented activity to improve this, including by introducing a hospital-based carer support worker (HCSW) role.

Healthcare Improvement Scotland's Unpaid Carers Improvement Programme has been working with local teams to understand how the HCSW role is improving the involvement of carers in hospital discharge.

The insights shared by local teams has identified important learning about the impact of the HCSW and the key elements that enable success. This includes:

- how the HCSW role as part of a multi-disciplinary team in hospital can enable earlier identification of carers, and their needs,
- how the HCSW role can provide the time and opportunity for conversations with carers that enable involvement and improves wellbeing,
- how the HCSW role can initiate the involvement of wider community services to support health and wellbeing of the carer in the long term, enabling the caring role to be maintained, and
- how the HCSW role can impact on staff experience and wellbeing by improving understanding and relationships with carers.

### Introduction

This report will be useful for:

- Frontline NHS teams interested in improving their approach to identifying, involving and supporting carers through hospital discharge,
- HSCP and third sector managers interested in improving their local HCSW activity and,
- Planners and commissioners with a role in ensuring sustainability and evidencing impact of HCSW roles.

Unpaid carers have a significant role in supporting and caring for patients following discharge from hospital. This not only ensures safety but also maintains patients at home and prevents readmission to hospital. It is therefore important that this role is recognised, and carers are considered as equal partners in how discharge is planned and delivered.

The Carers Act Scotland 2016 (Section 28) places the responsibility with health boards to ensure that carers are identified and involved in discharge planning.

Evidence shows that it often takes over 3 years for someone to recognise themselves as a carer, therefore relying on a carer to self-identify can be a particular barrier to involvement. Many carers continue to report that they do not feel supported or involved in the hospital discharge journey, often being omitted from discussion until the later stages leaving them feeling that they are not prepared or included.

The published evidence has shown that carer involvement in hospital discharge can reduce readmissions when a variety of support is provided. This can include support to identify carer needs, and to improve understanding of the tasks relating to providing care.<sup>1</sup> Current evidence-based recommendations for involving carers in discharge planning highlights the key role of having a central point of contact and information for carers, and designated roles for coordinating discharge with involvement of carers.<sup>2</sup>

Hospital based carer support worker (HCSW) roles have been commissioned in several local areas to provide a focused role within hospital settings to support carers. In this report we look at the role of HCSWs in involving unpaid carers in hospital discharge and what impact and learning there is from local teams regarding their approach.

To capture this learning, Healthcare Improvement Scotland's Unpaid Carers Improvement Programme worked with key staff in three areas of Scotland where these roles are well established. This work builds on the programme's evidence summary and mapping of current activity to improve carer involvement in hospital discharge in Scotland.

## Who we engaged with

The Unpaid Carers team gathered intelligence during conversations with local teams regarding their approach to HCSWs, collating common themes that were emerging regarding impact, enablers, and barriers.

Key staff from three local areas, Fife, East Ayrshire and Falkirk, participated in a series of semistructured interviews to capture more detailed insight. Staff interviewed included:

- Hospital-based Carer Support Workers who deliver the service.
- Carer Centre managers who design and monitor the service.
- Carer Leads in Health and Social Care Partnerships (HSCP) who commission the service.
- Frontline staff who work alongside HCSWs.
- Carers who have been supported by HCSWs.

	Year Started	No. of HCSWs	Commissioning organisation	No. and type of hospitals covered
NHS Ayrshire &	2022	2	East Ayrshire	2 acute
Arran			HSCP	2 community
NHS Fife	2017	5	Fife HSCP	1 acute
				6 community
NHS Forth	2012	2	Falkirk HSCP	1 acute
Valley				2 community

## The hospital carer support worker role

The approach to supporting carers through the HCSW role varies across Scotland. However, several common features can be identified as outlined below.

HCSWs:

- are based in hospital settings,
- have carer focused skills and expertise (see Appendix 1), and
- aim to improve the identification, involvement and support for carers during discharge planning.

The role of the HCSW may include:

- Raising awareness:
  - o with carers to recognise their caring role and rights,
  - with workforce to understand the definition of carer and the legal requirement to identify and involve carers, and
  - with workforce to understand the support available via HCSW and community carer organisations and their role in the local referral process.
- Supporting involvement in discharge by:
  - providing information to ensure carer understanding of discharge processes and decisions, including terminology,
  - o being alongside carer during discharge conversations with staff,
  - $\circ$   $\;$  sharing information between carers and medical staff, and
  - $\circ$   $\;$  attending discharge meetings and staff huddles.
- Providing carer support:
  - to identify needs and provide information and support where required, such as review of benefits, emergency plans and power of attorney,
  - o with referral to relevant carer agency or service for ongoing support,
  - $\circ$   $\;$  by signposting carers to other services in their communities, and
  - by initiating adult carer support plans.

"I start a lot of my conversations with the words – everybody here will have been talking about your loved one, I'm here to talk about you, the impact this is having on you and how we support you, because if we don't support you to remain physically and mentally well how will everything work going forward" (HCSW)

## Impact of hospital carer support workers

The introduction of the HCSW role has impacted on how carers are identified, involved and supported during hospital discharge planning. The role has also had an impact on the experience of hospital staff.

There is anecdotal evidence of the impact of HCSWs on the hospital discharge system, for example length of admission, number of failed discharges/readmissions. There is significant opportunity for improvement in this area, which includes identifying the cost benefit of these roles.

#### Carers are identified earlier

The identification of carers is the first step to enabling involvement in discharge planning. It also enables early conversations about the current home situation and where additional arrangements are required. Where HCSWs can have conversations with families during/soon after admission, the identification of caring roles and their impact can happen **earlier**.

At Crosshouse Hospital in NHS Ayrshire & Arran, the HCSW is based in the Combined Assessment Unit and through conversation with family and friends as part of the admission process helps to identify whether they have a caring role and how they are coping. This creates an early opportunity to build trusted relationships with carers and to share information about their rights, including what they can expect in terms of hospital involvement, and to offer a referral for support if needed.

"We did start by trying to base ourselves in the discharge hub. It was too late, because people were coming down there waiting to go home and families didn't always come in to take them home... so we linked in with the combined assessment unit... we're getting to actually meet families at the start of their journey" (Carer Centre Manager)

Often the carers being identified are early in their caring journey and are not requiring any additional support. The role of the HCSW is to provide information regarding where to find support if this situation changes. In 2023, a total of 871 carers were newly identified by the HCSW with 191 referred to local carer centres for ongoing support.

The conversation to identify carers can often be tricky and takes some time as many carers in the hospital setting will not realise that they are carers, for example because the caring situation has evolved over time or it's a new caring role due to a recent event. This can be a challenge for ward staff who are under increasing pressure, however the HCSW has the time to spend with carers, to build relationships and tease out this information.

"I'm approaching people who don't identify as carers and have no idea what it means, and some people will never get to the point where they say, "I'm a carer" but you can get to them looking after someone and here's some support" (HCSW)

#### Improved carer wellbeing

HCSWs are focused on the needs of the carer, their concerns and their wellbeing and take a personcentred approach to providing support. Having a role dedicated to carers ensures a single point of contact and enables the formation of trusted relationships that can reduce carer stress and improve wellbeing.

"when my mind was full and I was overwhelmed, I knew there was someone there just for me, who would listen to my concerns, who would treat me like an affected person, not just some random, they knew me, my dad, the hospital staff and the working of the system, it was a wonderful comfort to know I had that at the end of a phone or the click of a button during such a stressful period" (Unpaid Carer)

Taking the time to identify areas of concern for carers and being able to explain these to staff and provide reassurance and guidance not only reduces carer anxiety but can help to resolve issues and can have an impact on hospital discharge progressing as planned.

#### "It's giving us the opportunity to give families a separate sounding block. When there are concerns, they feel better for speaking to somebody who's not directly involved" (Occupational Therapist)

#### Improved carer understanding and involvement in the discharge process

The hospital system can be complex to navigate for carers. By being based within the hospital, the HCSW has a good understanding of this system and will spend time with carers to explain the details of the discharge process and potential outcomes. The HCSW supports carer involvement in discharge planning meetings, helping the carer to articulate their views, providing a level of advocacy and ensuring that issues that the carer is anxious about are raised.

"I really struggled at the start understanding all that was happening with my husband. I was in shock and couldn't think straight. She (HCSW) really helped me understand what was going on and helped me speak to the doctors to find out what I'd need to do when he came home. I was really worried and scared about that - she helped me by just listening to my concerns and talking them through which gave me confidence about what I could do and what I needed to talk to doctors about to get him home" (Unpaid Carer)

Ensuring carers understand the process and are involved in conversations can influence expectations and make a difference in terms of timely mitigation of concerns about new or increased caring responsibilities, or their home environment. There are also times where difficult decisions need to be made about the future and where support from the HCSW is really valued, for example where the caring role has increased and is no longer attenable and alternative arrangements are required.

"I think the focus in hospital is always very much on the patient. The HCSW role has allowed unpaid carers to be involved in that process a lot more, to be able to voice their feelings, their concerns, without judgment... it has really empowered carers to say actually I can't continue to do this" (Occupational therapist) In the Victoria Hospital in NHS Fife, the HCSW role was introduced in 2017 and developed as part of the discharge hub. The discharge hub is a team including social workers, senior nursing staff, and patient flow coordinators who assess and plan the discharge of patients that have ongoing care needs.

"We offer support for carers as part of the discharge plan... we are integral where carers have a lot of stress or something unforeseen has happened and there's going to be packages of care needed to go home safely" (HCSW)

Being part of the team enables the HCSW to identify carers and ensure they are involved and supported in discharge conversations from the outset.

"They are co-located with colleagues from the hospital and social work which enables more effective communication and a better understanding of who's being discharged where and when, that sort of thing, and particularly where there might be challenges" (HSCP Carer Lead)

As the HCSW role developed it was recognised that the needs of carers extended beyond those identified in the discharge hub. A referral process was introduced to enable staff from across the hospital to request carer support. In 2023, 1060 referrals were made to the HCSW from a wide range of staff and departments such as. consultants, social workers, and occupational therapists.

#### Identification of carer needs to continue in the caring role

The scale and impact of the caring role is often difficult to identify within a hospital setting. Through the relationship with the HCSW the carer is more able to reflect honestly and recognise where there are challenges in providing care. This helps to ensure the right support is put in place for discharge, such as small pieces of equipment or package of care.

"How you getting on with your caring role? they'll say "we get on fine" but then you discover he goes to the toilet holding on to a quad stick and she's 80 and she lowers him onto the toilet and sometimes he doesn't get there in time. I can pass on for assessment for a raised toilet seat" (HCSW)

The HCSW also aims to ensure that the carer's health and wellbeing is well supported in the long term by providing direct support such as income maximisation or referring to wider community support services like local carers centre or Alzheimer's Scotland. Ensuring all this support is put in place may prevent the carer reaching crisis following discharge, preventing an early readmission.

"The unpaid carer is supported in the most appropriate way that would allow them to continue that carer role. We would hope that would reduce the risk of readmission, that discharges are sustained over a longer period of time. It would hopefully prevent a longer stay in hospital because we're having those open, honest conversations about what their needs are" (Occupational Therapist)

#### Improved staff experience and understanding of the caring role

Support for carers was a previous gap in service provision, with staff aware there was unmet need. The HCSW role has provided a dedicated point of contact for carers that staff can refer to with the confidence that support will be provided. This has not only impacted on staff satisfaction and wellbeing but has also freed up their time to focus on other key activities.

"it's a really valuable role in supporting our role. We can pass on a lot to carer support and know that part is being dealt with. It frees up our time to concentrate on our role as OTs with the confidence that someone else is taking this on" (Occupational Therapist)

The HCSW is an important source of intelligence for staff and with permission is able to share feedback from carers. This has improved staff understanding of carer concerns, helped to mitigate problems and has improved relationships between carers and staff.

"There are situations where the HCSW spoke to us about the impact of what we were doing and what it was doing to the carer and we changed tack or changed the way we got on board with the carer. We see people at the bedside but they see them away from the bedside, it takes away the inhibition of carers being able to express their needs but we can still hear about it". (Palliative Care Consultant)

By raising the profile of the needs and expectations of carers, the HCSW role is influencing the understanding of staff regarding the impact of the caring role and the needs of carers to be able to continue. There is increasing recognition of the value of carers in supporting the patient after discharge and in preventing readmission.

"We're seeing people probably in a bigger state of crisis when they hit the acute side, we're seeing carers who are under significant carer stress, some carers who don't really identify themselves in that role. The biggest change has been acknowledging the role of an unpaid carer. For a long time it was an expectation that people will put themselves in that situation and will continue without any additional support." (Occupational Therapist)

## Key enablers

Several key elements have been identified that enable the HCSW role to be implemented successfully. These are outlined below.

#### Visibility of HCSWs

Being present on wards and wearing role identifying clothing ensures HCSWs are visible and recognisable to staff and visitors. Attendance at weekly team meetings increases visibility and is an ongoing reminder to staff of the importance of involving carers and the role of HCSWs.

#### Being embedded within a team

HCSWs being co-located and working within a team supporting hospital discharge has promoted recognition of the role and enabled carer needs to be identified and supported earlier. The HCSW role being valued within the team is demonstrated in several ways such as:

- Part of induction for new staff,
- NHS email address,
- Formal referral process in place, and
- Participation at ward huddles/multidisciplinary team (MDT) meetings.

#### Staff buy-in/effective referral process

An efficient referral process is essential to ensure that carers across the hospital have access to support from the HCSW. Where this works well buy-in from staff has been achieved when the referral process is light touch, not adding to workload, and considered to be worth the effort due to the positive impact of the HCSW. A key activity for HCSWs has been to raise awareness of the role and build relationships with a range of staff to encourage referrals.

#### Supportive leadership

Leadership roles both within the hospital and HSCP play an important role in planning, implementation and ensuring sustainability of HCSW roles. This includes:

- Enabling working relationships: recognising the HCSW as a valued member of the hospital team and promoting an uptake in referrals,
- Securing sustainable funding, and
- Ensuring the HCSW role is integral to the HSCP strategic vision/local carer strategy.

#### Partnership working with community services to ensure ongoing support

HCSWs work in close collaboration with local carer centres who can complete a full needs assessment with the carer when required and can provide a wide range of ongoing services and support following discharge, like access to short breaks, and counselling services.

## Challenges to implementation

Several challenges have also been highlighted that can act as barriers to the successful implementation of the HCSW role. These are outlined below:

#### **Carer identification**

Carers in hospital settings often don't know they are carers but will instead recognise themselves as a husband, wife, son, daughter and so on. HCSWs need to have very different conversations than if they were based in carers centres where people are actively looking for carer support. These conversations require a lot of skill and take a significant amount of time.

#### **Evidencing impact**

The collection of data to evidence impact of HCSW roles is currently limited and focused on the number of carers identified/supported and feedback from carers who have accessed the service. To ensure sustainability of these roles it will be important to implement clear measurement plans that include impact for carers, staff and the wider hospital discharge system.

#### Referral

Awareness raising activities with carers (such as stalls or banners) or signposting by staff has not been successful in encouraging carers to contact the HCSW. A staff referral process has been required to enable the HCSW to contact the carer directly. This requires staff buy-in and can be a challenge when staff are very busy. Carer identification and referral can happen too late, often when a problem is identified, and the HCSW has not been able to offer support.

#### Staff turnover

Raising staff awareness of carers and the HCSW service is an essential element of the role. However, due to high levels of staff turnover it is an ongoing and significant commitment. Activity can include running sessions for new staff, involvement in induction, providing yearly refresher sessions for senior staff/leaders, visiting wards to build relationships.

#### Capacity of HCSW

When referral numbers increase it can be challenging for the HCSW to provide support for all carers across the hospital. Where HCSWs have a role in completing Adult Carer Support Plans, this can be very time consuming, takes time away from activity to involve and support carers through discharge, and may not be the best time for carers to have these conversations.

#### Maintaining wellbeing of HCSW

HCSW are often involved in difficult conversations with carers and provide support at a particularly challenging time. This can impact on their emotional well-being and has been identified as an area where support is required.

## Recommendations for implementing a hospital carer support worker approach

The learning captured in the sections above identifies several key recommendations for designing and delivering a HCSW approach, this includes the roles of the HCSW, hospital staff and the hospital system. These are summarised as follows.

#### Planning the approach

- There is a clear aim of the HCSW role, for example to improve carer involvement and support during hospital discharge planning.
- HCSWs are based within a hospital and have access to staff and carers.
- HCSWs are appropriately trained, and support is in place to maintain their wellbeing.
- Measures are in place to identify the impact of the HCSW role on carer and staff experience and the discharge process. There is regular evaluation and reporting with opportunities identified for further improvement.

#### Early identification of carers and their needs

- System in place to identify/refer carers to HCSW during admission or soon after.
- HCSW has early conversation with carer to understand what is involved in supporting the patient at home, the impact of the caring role and any concerns.
- HCSWs are part of new staff induction training and support staff to understand the role of carers and importance of referral to carer support worker/service.
- HCSW have an ongoing role to raise awareness whenever possible through conversation and building relationships with ward staff.

#### Involving carers in discharge planning

- The HCSW has discussion with carer regarding the discharge process and their rights and role, including expectation regarding support for the patient at home.
- The HCSW is part of the MDT responsible for discharge planning and ensures relevant carer information is assimilated into discharge planning and decision making.
- HCSWs support carers to share their needs, views and opinions with staff.

#### Providing additional/ongoing support where needed

- The HCSW identifies carer needs and provides information and support in hospital where appropriate, such as income maximisation or power of attorney.
- The HCSW refers carer to local carer organisation for assessment/additional services when needed or to wider community supports, for example organisations like Alzheimer's Scotland.

## References and acknowledgements

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## Appendices

#### Hospital based Carer Support Worker - what qualities and skills are needed for this role?

#### **Qualities**

#### Demeanour

- Active / energetic
- o Calm
- Caring
- Confident
- Creative
- Empathetic
- Friendly
- Helpful
- Honest
- Observant
- o Open
- Passionate
- Patient
- Personable
- Realistic
- Reflective / reflexive
- Respectful / respected
- Self-caring
- Supportive
- Trustworthy

#### Attitude

- Accessible / Approachable
- Assertive
- Collaborative
- Determined
- Diplomatic
- o Driven
- Efficient
- Flexible
- Independent
- o Interactive
- o Non-discriminatory / judgemental
- Positive regard / respectful
- Pro active
- o Understanding

#### Desirables

- Carer lived experience
- Improvement skills

#### <u>Skills</u>

#### Communication

- Advocate
- Challenger
- o Complexity understanding
- Confident
- Contributor
- o De-escalation techniques
- Good conversations
- Emotionally supportive
- Interpersonal skills
- Involved (with boundaries)
- Listening skills active and empathetic
- Person centred
- o Relationship building skills

#### Leadership

- Autonomous/Self-management
- Co-ordinator
- o Critical thinking
- Crisis management
- o Forward planning
- Knowledge seeker
- Pivotal person
- Planner
- Problem solver

#### Workload management

- o Delegation/escalation
- Reactive
- Record keeping
- Technology
- Time management
- Workload planning



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