Good practice guide for hospital discharge:
Co-produced by unpaid carers, health care professionals and carer organisations

May 2023
About this resource

This Carer Aware resource is aimed at health board service planners, including patient flow and hospital discharge leads, and policy makers. It is also intended to be a source of information for health care staff with a leading role in hospital discharge, such as Discharge Liaison Nurses and Patient Flow Coordinators. This resource supplements the accompanying guide for frontline staff, ‘Involving unpaid carers in hospital discharge: a guide for healthcare staff’. It should be read alongside the Welsh Government’s forthcoming Discharge Guidance, NHS Wales’ D2RA Pathways and National minimum standards for the application of SAFER, RED2GREEN and Discharge to Recover then Assess (D2RA) in support of the 6 Goals for Urgent and Emergency Care.

This resource draws on roundtables and interviews with unpaid carers with recent experience of caring for someone being discharged from hospital, health board Carer Leads and professionals involved in the hospital discharge process from across Wales. Verbatim quotes and practice examples shared during the process are included throughout this document. These are supplemented by reference to national guidance, policy and relevant existing resources.

Recognising that our health and care professionals continue to work under significant pressures, this guide aims to facilitate an integrated approach to hospital discharge by meaningfully involving unpaid carers, third sector support and statutory and independent social care provision.

Why this resource

The point of discharge of a patient from hospital is often when many people become unpaid carers for the first time, or when their caring responsibilities become greater or more intense.

Ongoing pressures on the health and care service since the Covid-19 pandemic have seen unpaid carers face additional challenges and demands with regards to the care needs of their family and friends.

The hospital discharge process is a stressful time for many unpaid carers and crystallises some of the issues experienced by carers across the broader health and care system. Hospital discharge has also been an area of strategic focus for improvement for the health service and decision makers alike.
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Carer Aware

Carer Aware is a joint project between Carers Trust Wales and Carers Wales, funded by Welsh Government until 2025. It aims to transform recognition, respect and support for unpaid carers within health and social care services, and to empower unpaid carers to be actively involved in decisions and services for the people they care for and themselves.
Actions for a Carer Aware approach to hospital discharge

• Unpaid carer voice should be incorporated into Multi-disciplinary team meetings discussing discharge, either directly or through representation by a carer support service.

• Identified unpaid carers should be involved in every Discharge Planning Meeting, with a date agreed in advance.

• Clinical staff should inform unpaid carers, where appropriate, alongside the patient of the patient’s progress towards discharge, in line with SAFER guidance.

• Health boards should have established connections with regional or local Information, Advice and Assistance (IAA) services, with information for unpaid carers about hospital discharge and expectations in the hospital setting available both in hospitals and the community IAA service.

• Details of the Discharge Plan should be provided to identified unpaid carers, ideally in writing, including any relevant dates for MDT involvement. Where possible, this should include the anticipated date for allocating a social worker to the patient and, where relevant, the unpaid carer.

• Carer support services and related multi-disciplinary third sector organisations should be integrated within the hospital setting and the community coordination hub/single point of access.

• Specialist carer support should be sustainably funded or mainstreamed as part of the integrated hospital and community wrap around support. This could include carer organisations that have been commissioned to undertake statutory assessments, where appropriate.

• Clinical staff should involve carers in the patient’s ‘What matters to me’ conversations on admission and on an ongoing basis.

• Following the identification of an unpaid carer, relevant information should be recorded on the carer module of the electronic patient record.

• All settings should have a visible Carer Coordinator or Carer Support Officer on-site, employed by the health board or commissioned from the third sector, who has regular access to hospital wards.

• All clinical staff should be familiar with the process for onward referral of carers to the on-site carer support service.

• Clinical staff with an interest in working with carers should be supported to become Carer Champions in order to facilitate joint working between the carer support service and ward staff.
Policy context

“The nurses, you couldn’t fault the nurses... Where it all goes wrong is the system. They’re pushed. I know we’ve got a problem – we’re told every day on the news – but the hospitals now are getting more like factories: churn them out, churn the completions out.”

Carer with recent experience of caring for a parent who was due to be discharged from hospital.

Unpaid carers in Wales

Unpaid carers are the cornerstone of our health and care system, contributing upwards of an equivalent of £8.1bn annually in care, which would otherwise need to be provided by the paid workforce.

An unpaid carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

At the 2021 Census, 310,000 people in Wales identified as unpaid carers. This Census, set against the backdrop of the ongoing Covid-19 pandemic, recognised that people identifying as carers were providing higher intensity caring than in previous years, with 3.6% of the Welsh population providing more than 50 hours of care each week. Of those identifying as carers in the 2021 Census, 22,500 are young carers or young adult carers under 25 years old.

The true number of unpaid carers in Wales may be higher than the number recorded in the Census as not all people identify with the term ‘carer’. Instead, many people see themselves simply as a family member or friend.
Social Services and Wellbeing (Wales) Act 2014

Unpaid carers in Wales have legal rights. Under the Social Services and Well-being (Wales) Act 2014 a carer is defined as:

“a person who provides or intends to provide care for an adult or disabled child”¹

A carer can be an adult, a child or young person. Children have additional rights, including under the UNCRC and the Social Services and Wellbeing Act, and children and young people may have different needs to support their development than adult carers.

People who are caring, or intending to care for someone, such as those who are supporting a family member or friend being discharged from hospital who needs care as they recover or on an ongoing basis, have the right to:

- Access information, advice and assistance
- Be assessed if it appears they have a need for support, and to have all eligible needs met
- The Social Services and Wellbeing (Wales) Act 2014 is clear that a person must be “willing and able” to provide care. The extent to which a carer is able to provide care and willing to do so is assessed as part of the formal statutory Carer’s Needs Assessment. The Act makes clear that all professionals encountering people who need care and support are responsible for proportional assessments of a carer’s needs
- Exercise voice and control and be fully involved in decisions that affect them
- Access advocacy to support involvement in decisions

¹ Social Services and Wellbeing (Wales) Act 2014 Social Services and Well-being (Wales) Act 2014 (legislation.gov.uk)
Welsh Government policy context

Supporting carers through the hospital discharge process is identified within the Welsh Government’s Strategy for Unpaid Carers Delivery Plan 2021 as a contributing action to improving the identification of carers by professionals. In turn, this should aid service development that meets carers’ needs.

Since 2016-17 the Welsh Government has provided £1m funding to health boards to develop carer support. Health boards have invested in or developed their support for carers through the hospital discharge process, supporting delivery of the national carers’ priorities. Funding in 2023-24 is allocated exclusively to improve support for unpaid carers during the hospital discharge process.

More broadly, investment in carer support as part of the hospital discharge process is crucial to support implementation of ambitions in ‘A healthier Wales: the long term plan for health and social care’. Bringing care closer to home and facilitating flow from acute settings into the community is reliant both on the formal health and care community infrastructure as well as the often unseen hours of care provided by unpaid carers.

Discharge to Recover then Assess, D2RA

D2RA supports the Welsh Government’s 6 Goals for urgent and emergency care, delivering on the ‘Home First’ principle. It recognises that people may require a ‘settling’ or recovery period at home after discharge before being assessed for their ongoing care needs. It aims to take a ‘what matters’ approach, working with citizens to achieve the best long term outcomes.

This Carer Aware resource references D2RA practice and guidance where relevant with the view to providing a comprehensive approach to hospital discharge for discharge teams from the perspective of involvement and support for unpaid carers.

D2RA needs to be used in conjunction with SAFER and Red to Green guidance.

SAFER and Red to Green

SAFER aims to improve patient flow and optimise clinical outcomes for patients by involving people in shared decision making that leads to people returning to their own homes as soon as is clinically possible. Improving patient flow and optimising clinical outcomes involves ensuring that patients have value days – green days – where they are progressing towards recovery and discharge, and identifies ‘no value’ days – red days – where the person does not require the acute intervention provided by the hospital inpatient setting. A red day is when the patient would benefit from being in their own home or usual place of residence.
Voice and control: developing practice to involve carers in discharge planning

“So when you come to discharge you’ve got no control over it whatsoever.”

Carer whose husband was imminently being discharged from hospital to a care home

**Communication**

“It comes down to communication. We’ve lost the art of communicating, not just with each other but with carers.”

Ward Sister

“Communicate” is one of the underpinning principles of the D2RA model, which highlights that plans need to be communicated with all parties involved, including unpaid carers, if they are to be meaningful. Despite this, unpaid carers identify communication with professionals as one of the biggest barriers and challenges impacting their experience of caring for someone being discharged from hospital.

Honest and transparent communication is essential. Health care professionals should provide full explanations of a person’s condition, avoiding medical jargon, and of any care tasks they may need to undertake as a result of the cared for person’s condition when a person returns home.
Carer involvement

Carers should be empowered to be involved in the ongoing care of the person they care for, if that is their preference. This can support nursing staff with their capacity on the ward. Where it is possible and safe to do so, open visiting hours can support unpaid carers to sustain their caring relationship and ease transition from hospital to home at discharge.

A recognised unpaid carer should be involved in all discussions that affect them.

In line with D2RA guidance, clinical staff should involve the patient and the unpaid carer in meaningful conversations when considering the four key questions for D2RA at board rounds. Involvement of the carer is particularly crucial when considering questions 1, 3 and 4.

1. “Does the patient actually need any new care and support at home?”
   This forms the basis of the ‘What matters to me’ conversation, involving the patient and their unpaid carer.

2. Why not D2RA?

3. Is the patient physically/cognitively safe between visits/overnight?

4. Can the patient meaningfully engage in rehab/reablement?

Guidance states that this should involve positive shared decision making in collaboration with the unpaid carer.

This leads to a truly co-produced plan which is more likely to lead to successful and sustainable discharge.

Involvement of the unpaid carer, where appropriate and with the cared for person’s consent, should include:

- The cared for person’s assessment or ‘What matters’ conversation on admission and ongoing throughout their inpatient stay
- Coproducing the care plan, which will include Expected Discharge Date, Clinical Criteria for Discharge and their proposed D2RA pathway, as outlined in SAFER
- Discharge Planning Meetings
- It is only through meaningful involvement and consultation with unpaid carers that health care professionals will be able to arrive at an accurate and honest appraisal of what the carer is willing and able to provide after discharge
- While D2RA guidance rightly acknowledges the role of positive risk-taking to support people to return home as soon as possible, this should be balanced with an open conversation with the unpaid carer about how that risk might affect the level of care they are expected to take on. All plans that involve the unpaid carer’s provision of care, need to be coproduced between the patient/individual, clinicians and the carer. Again, an unpaid carer must be willing and able to provide care
- In some circumstances, Multi-Disciplinary Team meetings discussing the patient’s ongoing care needs
- Some people report that virtual involvement in MDTs, via Teams or Zoom, has led to greater feelings of involvement for unpaid carers. Where this is not possible or appropriate, a Carer Support Officer (or equivalent) can serve to share the carer’s views or advocate for them and facilitate communication about the patient’s condition after the meeting. Where relevant, a Trusted Assessor may be part of the MDT, leading to greater integration of care following discharge

“Being part of that MDT makes all the difference. I can then go back to my families and help keep them in the loop, tell them what’s happening.”

Carer Support Officer based in hospital setting
Where possible, dates for critical meetings, such as the Discharge Planning Meeting, should be agreed in advance with the unpaid carer. This will mean they can arrange time off from work or from other caring responsibilities to attend and will have the opportunity to prepare for the meeting in advance.

The emotional impact of caring for someone in hospital can be overwhelming. For many there will be the prospect of increased caring responsibilities on the cared for person’s transfer to home, or the prospect of transfer to a new care setting such as a care home. When a person does not feel able, or for reasons of accessibility cannot, contribute to these discussions, it may be appropriate to access the support of an advocate to facilitate the unpaid carer’s involvement and to allow them to exercise voice and control over the issues that affect them.

**Being informed**

Exercising voice and control as an unpaid carer is reliant on being fully informed about the cared for person’s needs after their discharge from hospital.

To support unpaid carers to access their right to information, advice and assistance, hospital services should provide clear information directed at unpaid carers about what they can expect in the hospital setting and once the person they care for is discharged. This should include information about how to access further information, advice and assistance through local or regional statutory IAA services about their caring needs and their right to request a Carer’s Needs Assessment.

An unpaid carer should be informed:

- Date and time of discharge, to be agreed with the unpaid carer, in line with the SAFER. All clinicians should be able to discuss and explain the Expected Discharge Date (EDD) and to do so in a way that is meaningful to the patient and the unpaid carer

- Where appropriate, unpaid carers should be informed alongside the patient of the progress the individual is making, including:
  1. What do you think is wrong with me? (Diagnosis)
  2. What is going to happen to me today? (Tests, interventions etc)
  3. What is needed to get me home? (Clinical Criteria for Discharge & Recovery Plan)
  4. When am I going home? (EDD)

In line with SAFER guidance.

- The Discharge Plan should be clearly communicated, ideally in writing, with the patient and their unpaid carer. While the content of the recovery plan will be developed after discharge, the Plan should include a clear summary with:
  - Immediate advice to support the patient
  - Which member(s) of the MDT will attend the first visit at home, and when this will take place
  - Contact numbers for queries

- Where possible and relevant, the period for allocating a social worker to the cared for person (usually within 20 days) to undertake an assessment of their need for ongoing care

- Where possible and relevant, the period for allocating a social worker to the unpaid carer to undertake a Carers Needs Assessment if it appears the carer has a need for support

- For unpaid carers of people at the end of life, the Advanced Care Plan

- A co-produced Recovery Plan, regularly reviewed and updated
‘Confidentiality’ should not be used as a blanket barrier to providing unpaid carers with information. Adult patients with capacity have the right to decide who is given information about their condition. Most people will, when asked, consent for relevant information to be shared with their unpaid carer or family member. Either way, an unpaid carer has the right to information that affects them, including any expectations or circumstances about the care they may provide after discharge.

In line with ‘More than words’, an active offer of Welsh language information should be made where this is reasonably practicable. Demonstrating respect for a person’s language identity will support involvement based on a relationship of respect.

- Unpaid carer voice should be incorporated into Multi-disciplinary team meetings discussing discharge, either directly or through representation by a carer support service.
- Identified unpaid carers should be involved in every Discharge Planning Meeting, with a date agreed in advance.
- Clinical staff should inform unpaid carers, where appropriate, alongside the patient of the patient’s progress towards discharge, in line with SAFER guidance.
- Health boards should have established connections with regional or local Information, Advice and Assistance (IAA) services, with information for unpaid carers about hospital discharge and expectations in the hospital setting available both in hospitals and the community IAA service.
- Details of the Discharge Plan should be provided to identified unpaid carers, ideally in writing, including any relevant dates for MDT involvement. Where possible, this should include the anticipated date for allocating a social worker to the patient and, where relevant, the unpaid carer.
Prevention and wellbeing: developing discharge services that support unpaid carers

Integrated, wrap around specialist unpaid carer support services spanning hospital to community.

Specialist unpaid carer support in hospital

Specialist unpaid carer support should have a presence in the hospital and the local social care community coordination hub/Single point of access to facilitate seamless transition from one setting to the other.

Carer organisations or services are best accessed early as part of a preventative approach. Being co-located with hospital staff and other agencies on the hospital grounds, such as with the Family Liaison Officer, social worker and other preventative services facilitates referral from clinical staff and direct access from carers.

Prior to the pandemic Carers Outreach’s Specialist hospital facilitator service was based at Ysbyty Gwynedd, co-located with partner agencies, Care and Repair and Age Cymru. Regular presence on the wards encourages ward staff to refer onwards. Co-locating support services enabled a partnership approach to meeting both the unpaid carer and the cared for person’s wellbeing and support needs.

Unpaid carer support within hospitals can include low-level advocacy to support meaningful involvement in assessments or Discharge Planning Meetings and can act as, or alongside, the Family Liaison Officer to ensure the unpaid carer is informed of the person’s condition.
Staff working in carer support, whether commissioned from the third sector or in-house provided by the health board, report that having presence and visibility on wards improves referrals and enables more unpaid carers to access the support they need. They report a proactive and ongoing approach to raising awareness and visibility of their service amongst clinical staff.

“We’re proud that there’s a person there for unpaid carers that staff can refer to. We work closely with our third sector colleagues. We put ourselves out there and people know how to contact us.”

Health board carer lead

Unpaid carer support as part of the local community support infrastructure

Supported and sustainable discharge services, as envisioned under D2RA and SAFER, relies on the necessary community infrastructure to provide the wrap around support needed by the cared for person on their return to home. This should include specialist unpaid carer support as part of a Multi-disciplinary team which offers home aids and adaptations, advocacy, social work and reablement.

Sustainable funding for community support is essential to facilitate patient flow in the longer term. Without reliable and longstanding support in the community, failed discharges are inevitable.

Integrated working

Seamless wrap around support from hospital to community requires an integrated approach to working. SAFER guidelines highlight the importance of effective communication between ward and community teams to facilitate early discharge. Early conversations with the community resource team or equivalent (GP, district nurse and social worker) support earlier discharge, with a subsequent review at home, in accordance with the D2RA model.

Integrated, effective communication may involve data sharing to enable a whole-system approach. Welsh Government is clear that data can be shared for the purposes of delivering health and care. This will include sharing unpaid carer data for the purposes of onward referral where the carer has consented. This has the benefit of facilitating transition from the hospital to the community setting.

“People don’t know who they’re meant to talk to. As soon as you’re out of the hospital, it’s people in the community, not at the hospital. It causes confusion for people.”

Ward manager

Employing the Trusted Assessor model enables one agency to undertake assessments on behalf of another. Many carers organisations undertake Carers Needs Assessments on behalf of the local authority in partnership with their social work colleagues in the statutory sector. Integrated working supports capacity in the health and care sector and minimises the number of agencies unpaid carers are referred to.

Swansea Carer’s Centre has been commissioned by Swansea Council to trial the undertaking of a proportion of Carers Needs Assessments in the local authority. By commissioning the same provider delivering carers hospital support in the area to deliver Carer’s Needs Assessments, carers in the area have consistent support at a time when they may be particularly vulnerable.
• Carer support services and related multi-disciplinary third sector organisations should be integrated within the hospital setting and the community coordination hub/single point of access.

• Specialist carer support should be sustainably funded or mainstreamed as part of the integrated hospital and community wrap around support. This could include carer organisations that have been commissioned to undertake statutory assessments, where appropriate.

**Identifying unpaid carers on admission**

Discharge planning begins when a patient is assessed on admission.

Professional views are a vital aspect of the assessment however the D2RA Guidance notes that ‘what matters to me’ conversations are highly likely to include more than the medical management of a person’s conditions. They will often include details relating to wellbeing and quality of life which should be co-produced between clinical staff, the person with care needs and the unpaid carer, who can be an expert on that person’s care. Without the involvement of the unpaid carer, crucial information about the person’s needs and circumstances could be missed.

“We often talk about a person's medical need – being medically fit – but carers provide much more than that.”

Ward manager

Guidance on D2RA outlines that information gathering as part of the initial assessment process includes early conversations with existing care providers in order to minimise the risk of deconditioning and plan for discharge. This will include existing domiciliary care providers and care home providers, where relevant. It should likewise include any unpaid carers involved in the provision of the individual’s care.

When an unpaid carer is identified, their details should be recorded (with their consent) to facilitate involvement of that carer throughout the patient’s time in hospital. Where training has been provided, clinical staff should record unpaid carer information on the new carer module of the electronic patient record.

• Clinical staff should involve carers in the patient’s ‘What matters to me’ conversations on admission and on an ongoing basis.

• Following the identification of an unpaid carer, relevant information should be recorded on the carer module of the electronic patient record.

**Onward referral for support**

“Supported and involved are two different things. From a ward perspective, we’re responsible for the patient... Involving someone might not mean they then have the support they need.”

Lead nurse

While every member of staff associated with discharge from hospital should be carer aware and approach unpaid carers based on the overarching principles to enable involvement through voice and control, clinical staff are clear that their primary remit is to ensure their patient is medically fit for transfer or discharge.
A well-defined onward referral pathway should be in place so that clinical staff can refer unpaid carers to specialist carer support within the hospital, following identification and recording on the electronic record. Clinical staff must know how to make onward referrals and this process should be simple and accessible. This will provide clinical staff with the confidence that identification of an unpaid carer leads to the support the carer needs.

At the Royal Glamorgan hospital in Cwm Taf Morgannwg, the Carers Coordinator has presence on the wards so that nursing staff are familiar with who to refer to when they identify an unpaid carer in need of support. Awareness of carer support, and how to refer to it, has been promoted through communications on the intranet and at hospital events.

“Rather than waiting for nurses to make referrals, I’m going looking for referrals. We will go to them rather than they will come to us. We can’t ask more of our nurses at the moment.”

Health Board Carer Coordinator

As nursing and clinical staff continue to face pressures within the system the proactive approach of Carers Officers, Carer Coordinators, Secondary Care Carer Facilitators to ward staff should be encouraged. Ward managers should encourage Carer support services to have regular presence on the wards. This serves to facilitate onward referral from nurses who may not have capacity to undertake a full referral process.

Once an unpaid carer is known to the Carer Support service, this service can undertake a ‘What matters to me’ conversation to assess the support they may need, whether this is access to preventative services in the
Carer Aware

community, to IAA or a referral for a statutory Carers Needs Assessment. The Carer Support services should work closely with the hospital social work team to facilitate referrals for statutory assessments and to coordinate assessments of care needs for the cared-for person prior to discharge where this is appropriate.

There is likely to be significant gaps throughout each week when the Carers Officer is not present on each ward. Carer Champions – clinical staff with a special interest in carers or who have received additional carer awareness training – can support their ward colleagues to direct unpaid carers to specialist provision at times when the Carers Officer is not present or accessible. They will champion carer support, be a direct link to the hospital Carers Officer and provide a constant support to colleagues in being carer aware.

Where the hospital carer support service is provided by the health board, links should be made and partnerships built with preventative third sector services that can provide wrap around support to the carer in the community following the discharge of the person they care for.

- All settings should have a visible Carer Coordinator or Carer Support Officer on-site, employed by the health board or commissioned from the third sector, who has regular access to hospital wards.

- All clinical staff should be familiar with the process for onward referral of carers to the on-site carer support service.

- Clinical staff with an interest in working with carer should be supported to become Carer Champions in order to facilitate joint working between the carer support service and ward staff.
Acknowledgements

Carers Trust Wales is grateful to the unpaid carers from across Wales who shared their experiences with us to inform this resource.

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References and related publications

Carer Aware/Carers Wales (2021) Good practice principles and tips for social workers: co-produced with social workers and carers Good_Practice_Principles_and_Tips_for_Social_Workersfin.pdf (carersuk.org)

Carer Aware project resources Carer Aware Resources for Professionals| Carers Trust Wales


Social Services and Wellbeing (Wales) Act 2014 Social Services and Well-being (Wales) Act 2014 (legislation.gov.uk)


Welsh Government (2022) Six goals for urgent and emergency care: policy handbook for 2021 to 2026 | GOV.WALES
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