

healthwatch

Blackburn with Darwen

A Dementia Friendly Discharge from Hospital



2018-2019

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Disclaimer:

This report is only representative of the respondents who have been affected by dementia and came forward to share their own experiences of a hospital discharge. Any safeguarding issues that were raised during the collation of this information were dealt with immediately and referred accordingly.

Glossary

Acronyms are used throughout this report, therefore for ease of reading the following glossary is provided.

BwD- Blackburn with Darwen

Healthwatch BwD- Healthwatch Blackburn with Darwen

DAA-Dementia Action Alliance

ELHT- East Lancashire Hospitals NHS Trust

PCH- Pendle Community Hospital

Enter & View visits- Healthwatch Blackburn with Darwen authorised representatives carry out these visits to health and social care services to find out how they are being run, gather feedback from patients and make recommendations where necessary. The purpose might also be to contribute to a wider Healthwatch programme of work.

Acknowledgements

Healthwatch BwD would like to thank the East Lancashire Hospitals Trust Patient Experience, Quality and Safety Team, the Complex Conditions Team and the Dementia Leads for supporting us to undertake this work.

We would also like to thank BwD Adult Social Care Service Lead for providing a deeper understanding of the discharge pathways and support after discharge.

We would also like to thank the Dementia Action Alliance, BwD Carers Service and our partner organisations for sharing information about this project.

A very special thank you is given to those who have come forward to share their own discharge experiences and are affected by dementia themselves or who support a loved one and family member without whom, this report would not have been possible.

Rationale

Improved quality of care in general hospitals is one of the top four priorities being considered by the Department of Health in their dementia strategy.

It was identified in the National Audit of Dementia (2017) that Royal Blackburn Hospital received a 64% rating for the 'extent of planning for discharge from hospital for people with dementia, hospital transfer and how adequately carers were informed'. The mean average score across England and Wales is 73%. NICE produced guidelines and made recommendations for health and social care professionals in June 2018 (NG97), to help improve the assessment, management and support for people living with dementia and their carers. These recommendations form the basis of ELHT's Dementia Strategy 2019-2022.

ELHT has now signed up to the Dementia Friendly Hospital Charter and is proactive in ensuring that best practice guidelines are achieved.

Healthwatch BwD would like to give a voice to those affected by dementia including family and carers who have experienced a hospital discharge in the borough of Blackburn with Darwen and transition back to their own home or residential care.

Methodology



The Dementia Leads for ELHT were instrumental in supporting us in this work and helping us to understand the different discharge pathways. A Healthwatch Representative was invited to experience the 'Virtual Dementia Training' to demonstrate the Trust's commitment to be a Dementia Friendly Hospital.

To develop a greater understanding of the different discharge pathways we met with BwD Borough Council Adult Social Care Service Lead. We discussed options for how support, if required, is implemented for people returning to their own homes. Our aim was to speak to patients, carers and family members using four themes, devised from the DAA Dementia Friendly Hospital Charter, and the Hospital Discharge pathway.



The themes are as followed:

1. Preparation for discharge
2. Communication between staff, carers and families, especially at the point of discharge
3. Support services post-discharge
4. Coping post discharge

(See appendix 1, page 25; ‘The Four Main Stages of Discharge’).

Partner organisations, supporting those affected by dementia, were asked to share information about this project to give service users the opportunity to tell Healthwatch BwD about their experiences.

We also undertook three Enter & View visits at:

- Royal Blackburn Hospital, Ward C5 (dementia friendly medical ward for older people)
- Springfield Care Home (registered care categories include dementia and rehabilitation)
- Eachstep Blackburn (specialist dementia care service)

Ward C5 was chosen for its exemplar dementia friendly environment and to gather feedback at the point of delivery on the first two themes, ‘Preparation for Discharge’ and ‘Communication between staff and carers’ during the discharge process.

Visiting the care homes allowed us to gather feedback from the Provider, relatives and residents that had experienced a discharge to one of the homes.

Through our engagement we had in-depth conversations with twenty patients, carers and family members who have been affected by dementia and have experienced a hospital discharge. From these we sampled six patient journeys, which are reflective of all our discussions, to analyse further within this report.



Background information

Discussion with East Lancashire Hospital Trust regarding their discharge pathway process.



From speaking to the Senior Case Management Lead and Dementia Lead for ELHT it would appear that they are supported to deliver the Dementia Friendly Hospital Charter best practice guidelines.

As can be seen from the Enter & View report (Appendix 3) following the visit to Ward C5, many initiatives have been implemented to support people's experience in hospital who also have dementia. The Complex Case Discharge Team consists of four leads that support staff on the wards with complex case needs and include a Social Worker, Physiotherapist, Occupational Therapist, and Nurse leads.

As part of the training framework established in 2012, every new member of staff at ELHT undergoes training to become a 'Dementia Friend' and may experience a 'Virtual Dementia Training' to gain insight about the effects of dementia. Each ward within the Trust has a link nurse who is offered updated dementia training four times a year.

"The staff spoke to me and not just my spouse. It was obvious that they knew how to support someone with dementia and had been specially trained."

When discussing discharge pathways, the Complex Case Discharge Lead informed us that there are different pathways to discharge depending on assessed need and funding decisions. Their aim is to get patients discharged from hospital in a timely and safe manner.

To fulfil this aim and improve patient experience, the ward has clear processes for planning, admission, welcome and introduction, delivery of care, review of care plans and transfer of care at discharge. At the point of discharge a discussion between staff, patient and family should take place. When patients are admitted from home and assessed as medically fit to be discharged a 'Home First' trial is arranged to see what support, if any, is needed.

The Complex Case Discharge Team take a referral from the ward for a patient to be assessed at home. One of the team takes the patient home by car to assess the home for adaptations and other support that may be required.

Requirements for adaptations are reported to be made within the first 24 hours of discharge, where possible. Crisis support can be provided 24 hours a day for a maximum of three days. If longer support is needed a package of care can be arranged following a further assessment. There is a lead named professional who will visit three days post discharge to see how the patient is coping.


We were told by the Complex Case Discharge Team lead that this process has seen a reduction in readmissions to hospital, especially for those with dementia.



Discussion with Blackburn with Darwen Adult Social Care Lead regarding their discharge pathway process.

Again, there are several different pathways professionals can follow depending on the assessed needs of the discharged patient and associated funding decisions.

Senior managers and frontline staff co-designed a Trusted Assessment Document. This follows the patient through hospital and allows everyone involved in discharge planning to update it. An integrated step-down team was established to receive the



Trusted Assessment Document and determine which pathway was most suitable for the patient. This was piloted in October 2016 with ‘Home First’. Using the Trusted Assessments to coordinate discharge to reablement, sub-acute support or residential rehabilitation, is now embedded in the discharge process.

Ward staff undertake a pre-discharge assessment on the ward before the patient is discharged to their home. There is a full assessment on day three within the patient’s home. Wrap-around care is offered for up to five days post discharge, during which time multi-disciplinary care staff help to enable the individual as much as possible and introduce voluntary and community organisations for additional support.

‘This has been implemented in partnership with Lancashire County Council, East Lancashire Hospitals NHS Trust and Lancashire Care NHS Foundation Trust, to achieve a more consistent discharge route for people, wherever they live.’

(Blackburn with Darwen Home First with a trusted assessment: 19 Jan 2018)

Service user experiences

Patient and carer journeys from inpatient point of discharge and beyond have been recorded and themes have been identified and recommendations made for both health and social care providers.

It is intended that the patient, carer and family members accounts included should be read in full so that all stakeholders can understand how people are experiencing their services.

“Professionals working across health and social care need to understand the journeys taken by the people they care for”. (Beyond barriers 2018 CQC)

This report is only representative of the people who came forward to share with us their own experiences. 20 patients, carers and family members shared their experiences. Six varied patient journeys have been included in this report and five occurred within the last twelve months. Patients discharged from Royal Blackburn Hospital to a Lancashire post code have also been included as they have followed the ELHT discharge pathway from RBH.

It is important to note that respondents were mostly happy with the care that they or their loved one had received whilst in hospital and spoke of how hard the staff work.

The following patient journey, (Betty) is an account of a service users experience before the establishment of BwD Adult Social Care integrated step-down team to receive the trusted assessment document and coordination of discharge to reablement, sub-acute support or residential rehabilitation. It has been included for comparison in the summary of feedback to determine how it has impacted on the discharge process and after care of vulnerable adults. It has not been included in the patient journey analysis.

Patient Journey One: Betty

Betty used to live independently in her own flat but after several admissions to hospital and advancing dementia she moved into a care home following an initial short-term respite stay.

Hospital discharge experiences to Home

As family carers we were not involved on the first three occasions that Betty was discharged from hospital to her home and no discharge planning was discussed with us. She was returned to her flat by hospital transport.

We felt our needs as carers were not given a second thought. Our contact numbers were given to the ward staff but rarely used on the first few discharges to home. When it came to discharging our mother to home no consideration was given to the timing of discharge or to us receiving her home. We made three different appointments to speak to the doctor managing her care, none of which were kept as he was needed elsewhere. This was very difficult for us as we had full time jobs. We did not feel listened to or valued.

On one of the discharges to her own home, a social work review was held, and we were asked how much care we were able to provide. A list of services was given to us that could provide support and help but many of them were no longer in operation or Betty did not qualify for them. Also, some of the services didn't have the flexibility to support someone whose family were at work during the day and required a support person during these hours. We agreed to provide all evening and weekend care if daytime support could be provided by the local authority.

Betty was given a personal budget which funded only 12 hours of support per week, but we were able to use this with reasonable success. The family arranged a volunteer via CVS to help but this still left a lot of unsupervised hours.

Betty had an agency care worker calling each morning to assist with dressing and personal care, but she was frequently out before they arrived because they could not attend before 10am. Betty often went out not properly dressed and wearing slippers as a result. They would wash up and leave a sandwich which would still be there when we came after work.

We saw no other health professionals after the review and no goals were set. We had to solve our own problems. On different discharges, medication would arrive after a day or two, usually with an information leaflet in the packet. Often the different medications were out of sync, i.e. ten days of one type of meds, two weeks of another, four weeks of another, so we were never away from the pharmacy re-ordering her prescriptions.

Eventually Betty went into a care home to give the family some short respite, which was a last resort as this was not what everyone wanted. This quickly turned into a permanent place because she had to give up her flat in sheltered accommodation as the provider wanted to offer it to someone else.

Hospital discharge experiences to a care home

On the fourth and fifth occasion, when she was then living in a care home, she was again dropped off by hospital transport.

I don't know how much consideration was given to the care home, but I think Betty arrived back without warning, without medication and without any information about treatment.

The care home struggled to find out what medication Betty had left hospital with until it arrived at the home a few days later as the prescription went directly to the pharmacy and the medication did not arrive for 24-36 hours later. The care home staff knew nothing about the medication or even the outcome of the admission as the ambulance crew returning her to the home had little information.

Betty was just sent back to the care home with no diagnosis or information about what had caused her condition leading to her hospital admission. When we contacted the hospital, all her symptoms were just attributed to Alzheimer's.

Betty was a very independent person and went into care because her family, despite reducing our working hours, could not afford to give up work altogether. She lived at the care home for just over twelve months. In that time, she was admitted to hospital five times and was discharged with no proposed treatment or changes to

her care. On each occasion, she spent hours in the hospital corridors waiting for a bed.

On her last admission to hospital she passed away without any family members present. This was despite ringing the ward and asking if one of us could sit with Betty through the night. The hospital ward told us there was no need as they would contact us if things changed. They rang us in the early hours of that same night to inform us that she had passed away 'suddenly'.

Overall, although only 20 months have elapsed since Betty passed away, Alzheimer's and Dementia services in general seem to have become more easily available and more widely known and accessible.

Every person we encountered was pleasant and genuine, but services were poorly coordinated, many relied on volunteers or short-term funding and had waiting lists. Communication between hospital and home and care home was affected by shift work and poor follow up. There was limited social work input, no named regular contact person either in hospital or in adult social care and often, not even in the home. Of these, I think a named contact person at the hospital would have been most beneficial, even someone who could email a short report to family and care home regarding the discharge date, time, diagnosis, treatment, medication and information would have been so helpful.'

"No family members were involved at all on the first three occasions that Betty was discharged from hospital and there was certainly no discharge planning discussed, she was just returned to her flat".



Patient Journey Two: Amina

Amina was initially admitted to Royal Blackburn Hospital on one of the B wards following a stroke. She also has dementia. Amina was in hospital for three weeks and the care was very good. As carers and family, we were kept informed about the discharge process and given information about managing her stroke.

Amina followed a Blackburn with Darwen discharge pathway. This story is told from the perspective of her daughter.

Preparation for discharge

I was informed that Amina was medically fit for discharge and the doctors and nurses advised that she be transferred to Pendle Community Hospital for more rehabilitation for her condition. Myself and the family were happy for this to happen. However, the Consultant decided that rehabilitation in a designated care home environment, in the Blackburn area, may be a better option.

The hospital social worker was our contact whilst Amina was in hospital.

As a family we were listened to and felt involved in the discharge planning. We were happy with the hospital staff and the care provided.

Communication at discharge

Amina cannot speak English and as her main care giver within the family I would normally translate for her. I did not have power of attorney so was not allowed to discuss her options or translate her wishes. The social worker at the hospital provided interpretation.

“The interpreter could not understand Amina and I was not allowed to help in case I translated it differently.”

The social worker/interpreter put my family off considering rehabilitation in a care home, giving examples of their own poor experiences and stating that it would look bad on the family if we did not take her home. It was decided by the family that I would bring her home to live with me.

We were partly made aware of services post discharge but my needs as the primary carer were never considered by anyone.

I was told about the Stroke Association, who have been good, and I was advised that social services would put in a care package. I was also told about carers services in Blackburn.

Support services post discharge

Post discharge I presume the nominated health professional was the social worker because we did not see anyone else. Amina lived with me for 2 weeks after discharge within which time a stroke assessment was undertaken. I was also given a carers assessment.

Coping Post Discharge

After living with me for two weeks Amina went back to her own home, where she was assessed again by different social worker from the adult social care team to determine her needs. She was not able to manage the stairs or access her bathroom so was given a commode downstairs. Other significant housing needs were identified and have taken five months to be addressed. Her dementia is getting worse due to the stroke. The care package is inadequate for her needs and the carers cannot communicate with her due to language differences. The carers often forget to give her medication and I have raised this with the care provider, but it continues to be a problem.

“She was in hospital for three weeks and the care was very good. I was kept informed about the discharge process and I was given information about managing the Stroke”.

“My needs as the primary carer were never considered by anyone”.



Findings from the five more recent patient journeys

(Excludes Patient Journey One, Betty. Patient journeys three to six can be read in the appendices).

1. Preparation for hospital discharge

Comments from four out of the five patient journeys suggested that they had received some information about discharge planning and discharge arrangements. (Two respondents had more than one discharge experience with their relative). Two out of four carers/family members were told how to manage their relatives' condition and made aware of what would be required post discharge in terms of the impact of care needs.

“I don't feel involved in the discharge process of my relative and don't know what to expect when they come home”.

“We both felt listened to and involved in his discharge planning”.



2. Communication between staff and families/carers at discharge

Two out of the five patient/carers said that they had felt involved in the discharge planning, had been listened to, and felt valued.

One carer felt that their needs had been considered in the process.

Three out of the five patient/carers were not offered symptom and medication management advice on discharge.



Two out of five the patient/carers said they had not been made aware of services post discharge and one respondent said they had only been given some leaflets. Four out of the five carers stated that their needs were not considered when discharging their relative home.

One couple who were completely satisfied with their discharge experience had not required any home care support post discharge.

“We were not made aware of what services could support us after discharge and our needs were never considered. We were however involved in the discharge planning.”

“He was sent home with adequate pain relief so that he could continue to get around at home, with clear instructions written down of how to manage the pain medication.”

“We both felt listened to and involved in his discharge planning”.

3. Support services post-discharge

The greatest dissatisfaction from respondents about the care and support post discharge, was that it was either not in place, or that it was inadequate and poorly coordinated.

Respondents were not always aware of a nominated health professional and no one appeared to have been offered a six-week intervention with goal setting.

Medication was not always available on discharge, with significant distress being experienced by one gentleman and his carer resulting in a failed discharge and return to hospital.

Provision or support with personal care did not always appear to be adequate with some carers having to cope for a few days until the crisis team could be contacted for additional support.

Respondents said that hospital staff and social workers did seem to consider the wishes of the person affected with dementia regarding discharge. However, some family members and carers felt their input and their ability to cope was not always considered. Two respondents questioned the effectiveness of the capacity assessment and best interest decision taking place on the ward to determine if the patient fully understood their options and how they would cope at home after discharge.

Home First was the main pathway at discharge for the respondents in the patient journeys, whether being discharged to a Blackburn with Darwen post code or a Lancashire one.

“As the main carer I felt pushed away from the decision making and felt I had no say in the discharge process. “I felt like the decision had already been made without any considerations for me or our ability to cope”.

4. Coping post discharge

Out of the five patient journeys two people were readmitted to hospital.

Two respondents reported that the GP had disagreed with the hospital's decision to discharge, with one GP needing to readmit the patient resulting in a failed discharge. One respondent felt that better discharge planning and support could have prevented readmission to hospital.

From the feedback we received from the patient journeys there appeared to be less satisfaction with the immediate support post discharge, i.e. the first 72 hours.

One patient journey from hospital to a care home suggested that the communication and discharge planning could have been better. In addition, it was reported that the manager and staff at the home had to chase up the hospital and GP to find out if she needed any further treatment as no discharge notes were sent with her.

Healthwatch BwD undertook an extended engagement to this project to gather the experiences of vulnerable adults discharged to residential care to ensure that this sector is represented in the transition from secondary to primary care as one case study suggested that communication with the care home at discharge could have been improved.

See report '**Discharge experiences of vulnerable adults to a residential care setting**'.



Improvements reported by those experiencing a hospital discharge experience after 2017.

Below is a reflection on the main issues raised in the first patient journey; 'Betty', compared with the five more recent experiences.

Betty

- Family and carers were not involved in the discharge planning on any of her many hospital admissions
- The main carers did not feel listened to or valued
- The main carers needs were never considered
- No medication advice or information given to main carer when discharged to her own home. Some information about services post discharge were discussed but these were out of date or not appropriate for Betty's needs
- No consideration was given to the timing of any of the discharges
- No discharge information was provided to the main carer about how to manage the condition
- No professional contact was named pre or post discharge which would have been helpful
- The post discharge social care package and support was inadequate and overnight care was not available when it was needed
- Lack of communication with care home when returning back from an inpatient hospital stay

The main areas of improvement since 2017:

- Most carers indicated that they had been involved in the discharge planning.
- Some respondents had indicated that they had been given some practical advice to manage their condition once home.
- Feedback from respondents indicated that the timing of discharges had been appropriate.
- Most respondents were aware of a contact person, mainly a social worker, or had a contact number following discharge.

Areas that appear to still need improvement:

- Most of the respondent carers and family members expressed that they did not always feel listened to or valued. All but one respondent said that the carers needs had not been considered.
- Some of the respondents in the patient journeys indicated that advice and information about medication was still lacking as was information about services available post discharge.
- Some of the respondents who had needed care and support post discharge had said that this had been inadequate immediately after discharge, with two patients being readmitted to hospital within a short time frame of returning home. Despite the introduction of the Crisis Support Team which can be provided 24 hours a day for a maximum of three days post discharge, overnight care appeared to be unavailable when carers in the patient journeys reported being in crisis.
- The need for clear communication about discharge planning with carers and close relatives, especially those who provide day to day care was identified in an Enter & View visited to ward C5 at Royal Blackburn Hospital and in the patient journeys. (See Appendix 3 for link to report).



Healthwatch Blackburn with Darwen

Recommendations:

Recommendation 1:

All professionals in the discharge pathway should ‘ensure that carers are involved in discharge planning, feel they have been listened to, feel valued and have their needs considered in the process’ in line with the Dementia Action Alliance recommendations and NICE Guidelines.

“Adults with social care needs have family or carers involved in discharge planning if they are providing support after discharge.” NICE Guidelines (Quality Statement 136. Standard 5 (2016))

Recommendation 2:

There should be clear communication with the carer or those who provide day to day care, about discharge and support arrangements. It would be helpful if this included the name and contact details of the nominated health professional. This should be in written format, without breaching confidentiality, so that there is something to refer to after leaving the ward following discharge.

“Adults with social care needs given a copy of the plan for their move out of hospital before they leave. The plan should be easy for them to read and understand, and people giving them this information should also offer to explain it to them.” (2015) NICE guideline NG27, recommendation1.5.16

Recommendation 3:

Clear communication about any prescribed medication and management of the person’s condition should be discussed with the main carer if the patient with dementia has difficulty retaining or understanding information.

“Health and social care practitioners should discuss relevant information about medicines with the person, and their family members or carers where appropriate, at the time of transfer. They should give the person, and their family members or carers where appropriate, a complete and accurate list of their medicines in a format that is suitable for them. This should include all current medicines and any

changes to medicines made during their stay”. (NICE Guidelines, communication during transfers of care, medicines optimisation)

Recommendation 4:

Professionals should not influence the decision of the patient, family or carer. Impartial information should be provided about the choices available, to allow the patient and main carer to make informed decisions.

“The social worker/interpreter put my family off considering rehabilitation in a care home, giving examples of their own poor experiences and stating that it would look bad on the family if we did not take her home”.

Recommendation 5:

There should be clear communication and effective coordination, irrespective of where a person is discharged to, of post discharge treatment, support and information ensuring that adequate care packages are in place.

Services that can offer additional help, advice and support should be discussed with the patient and main carer as appropriate.

“Ensure that the person, their carer and all health and social care practitioners involved in someone's move between hospital and home are in regular contact with each other. This is to ensure the transition is coordinated and all arrangements are in place. (NICE guideline Published: 1 December 2015 [nice.org.uk/guidance/ng27](https://www.nice.org.uk/guidance/ng27))

East Lancashire Hospitals NHS Trust gave a full response to our findings and Christine Pearson Executive Director for Nursing and Andrea Isherwood, Head of Complex Case Management have noted the comments and recommendations which have been shared within the Directorate and the Intermediate Care Board.

The Service Lead Intermediate Care Manager for BwD Adult Social Care has also provided a response which is included in this report.

TRUST RESPONSE

Re: Response to Healthwatch Blackburn with Darwen draft reports:

**A Dementia Friendly Discharge from Hospital draft report
Discharge to Care Homes Draft report**

The findings from the draft reports have been shared with Christine Pearson, Executive Director of Nursing for East Lancashire Hospitals NHS Trust.

"I would like to thank Healthwatch Blackburn with Darwen for undertaking this valuable piece of work. The Trust constantly strives to ensure all our patients have the best possible experience when using our services. We take all feedback very seriously and will be taking on board the feedback and recommendations."

The Transition Safely Improvement Project is a multidisciplinary & multi-organisational improvement activity looking at transition safely from ward / unit to destination.

The Improvement Practice Team have engaged with key leads and individuals and are working on a number of focus areas including:

- Draft admission and discharge care bundles have been formulated and are currently in trial on a specialty acute ward and a non-acute Medicine For Older People ward.
- Creation of consistent approach for junior doctors in respect of the Transfer of Care letter.
- Creation of consistent approach for effective communication with the patient and their family / carers.
- Timely access to speech and language therapy to inform safe discharge, with regard to swallowing and potential use of thickeners.
- Embedding the SAFER principles on the ward;
 - S – Senior review. All patients will have a senior review before midday
 - A – All patients will have an expected discharge date and clinical criteria for discharge.
 - F – Flow of patients will commence at the earliest opportunity from assessment units to inpatient wards.
 - E – Early discharge.
 - R – Review. A systematic multi-disciplinary team review of patients with extended lengths of stay
- Daily Multi-disciplinary meeting to be held on wards reviewing all patients and care plans (Mon-Fri)
- The Red Bag Scheme. For patients admitted with red bags, an icon has been added to the electronic patient system to be used when patients commence their journey in the Emergency Department. This should prevent bags being lost and ensure that they are returned to the home with patients on discharge.

Safe | Personal | Effective

Blackburn with Darwen Adult Social Care response to this report

I have had the opportunity to be consulted as part of the report and have now read the final version. It is important to highlight that service user and carer feedback is fundamental to improving and developing our services that adequately meets care and support needs whilst maintaining the principles of promoting a person's independence.

We continue to welcome all feedback to improve the quality and experiences of local people within the Borough and this report is no exception.

Over the last four years, as a health, social and voluntary care system, we have positively worked in partnership to develop smarter pathways to improve experiences of hospital discharge and ensure those that can go back home after a stay in hospital, have the opportunity to do so. It is imperative that all professionals take into consideration the wishes and feelings of the person and the people who are important in their lives and support them and assist in the planning when making decisions.

Carers Assessment are an integral part of social care assessments and offered to all carers. In addition to this, Blackburn with Darwen also has a Carers Service that 'brings carers and the carers service together as expert partners to ensure carers needs, wishes and feelings are at the heart of everything they do'. The department will continue to ensure that all practitioners, as part of their integrated ways of working within neighbourhoods, are kept up to date with all community service developments and offers to ensure that local people know local service offers and are directed and/or referred accordingly to the right service.

Goal setting is an essential component of effective interventions to those referred into Intermediate Tier (adult social care) and receive a 'home first service' or rehabilitation offer. Practitioners having the right conversations with people in a way that they can understand and contribute to, will continue to be embed in practice as we carry on driving person centred, strength-based approaches to care and support.

It is important to highlight that recent evidence of people who reside within BwD and who have a diagnosis of dementia, in the main have done exceptionally well using our Home First services. Assessment that takes place within a person's own home rather than on a hospital ward, offers an opportunity for recovery within familiar surroundings, which has been proven a success to ensure independence as far as possible, is maintained.

Appendices:

Appendix 1: Four Main Stages of Discharge from Hospital that supports those affected by Dementia

The Four Stages of Discharge that supported conversation and feedback are on the best practice guidelines for hospital discharge for people affected with dementia.

1. Preparation for hospital discharge -

- Are family and carers being informed about discharge arrangements and management of conditions.
- Were family and carers aware of what would be required post discharge in terms of the impact of care needs whether home care or nursing home provision and possible costs?

2. Communication between staff and families/carers at discharge -

- Are they made aware of services post discharge?
- Did they feel listened to and valued?
- Were they involved in the discharge planning?
- Were family & carers needs considered?

3. Support services post-discharge What support is put in place post discharge for carers and how did services work together?

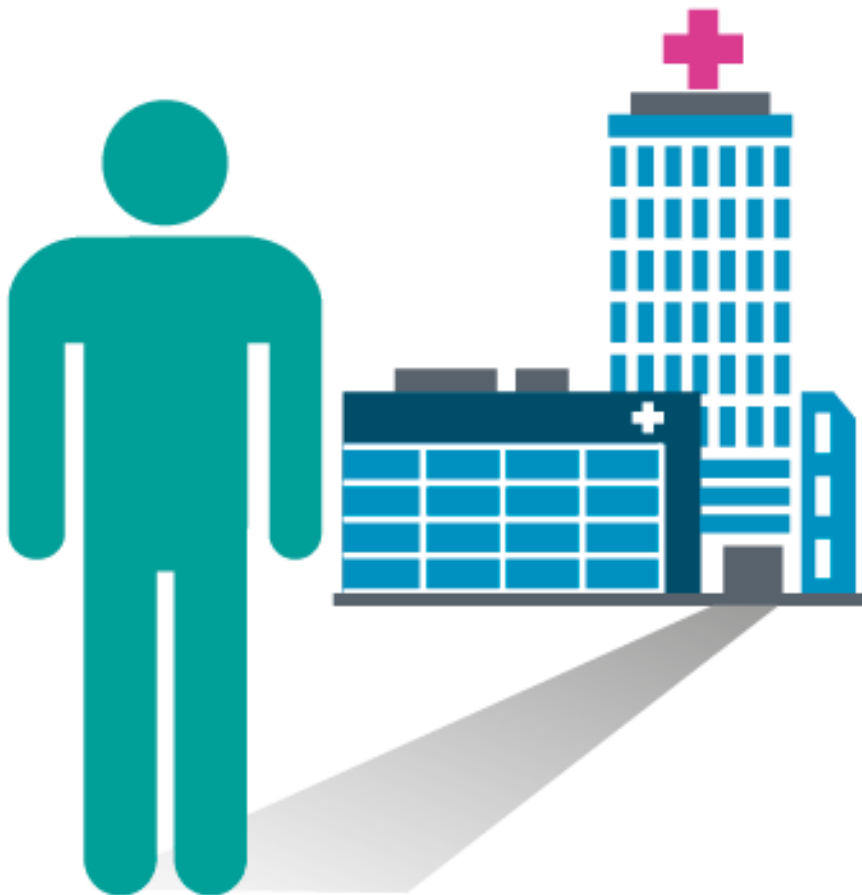
Example-guidelines from the Dementia Specialist Care Models

- Care packages should be tailored to meet the individual's needs. (Person Centred)
- There should be a nominated health professional post discharge, offering information, identifying problem areas, symptom management and interventions, providing a link for long term planning. (6-week intervention and goals set).
- Timing of discharge the should be considered around the person's needs.
- Medication should be available on discharge and support in place to give it where necessary.
- Provision or support with personal care should be organised where required.

- Was the person affected with dementia and their family or carers wishes considered as to where they wanted to be discharged to? For example, (home with care a package or short term residential with rehabilitation or pressurised into a long-term care home place not really of their choice rather than availability?)

4 Coping post discharge -

- How have things turned out? Has there been a readmission to hospital?
- If yes, was it avoidable? (Was 6weeks intervention from nominated health professional helpful? Was it long enough etc. (“understanding of ability to cope, patient's impairment and family conflict over care can lead to unnecessary re-admission to hospital or long-term care.” Could this have been avoidable if appropriate discharge assessments and planning had been undertaken?)



Appendix 2:

Four further patient journeys of the hospital discharge experiences that have occurred within the last 12 months.

Words and phrases are not those of Healthwatch BwD but transcripts of what carers, family and a service user told us.

All names are fictitious and stock photographs have been used. All attempts to remove identifying features have been made.

Patient Journey Three: A Couple's Story

(Spouse) My partner has early onset dementia and is still quite independent except for some memory issues which is made worse when he is worried or stressed. He was admitted to hospital due to severe back pain following a previous accident. It took 12 hours from calling the GP to getting an ambulance to transfer him to hospital A&E. The ambulance crew were great and managed his memory problems well.

(Spouse) I could stay the whole time he was in hospital because of John's campaign. I was given the ward number and invited to stay 24/7 if I wanted to.

(Patient) The ward staff were great and treated me 'normally', not just focussing on my dementia. They spoke to me and not just my spouse. It was obvious that the staff knew how to support someone with dementia and had been specially trained.

(Patient) Once I was at Royal Blackburn Hospital my pain was controlled and managed well. The staff were so pleasant, nothing was too much trouble for them. They were so busy they never stopped. The staff work incredibly hard and are very nice.

(Spouse) I was kept informed throughout his stay and about his discharge planning. We were both told how to manage the condition that was causing his pain, we already knew about his dementia because he had already been diagnosed for some time.

The best aids to support his walking were discussed and he was provided with crutches prior to discharge. His ability to walk with crutches and manage the stairs at home were assessed, as were home adaptations, which he did not need in the end.

We both felt listened to and involved in his discharge planning. He was sent home with adequate pain relief so that he could continue to get around at home, with clear instructions written down of how to manage the pain medication.

No other services were needed post discharge.

“We both felt listened to and involved in his discharge planning. He was sent home with adequate pain relief so that he could continue to get around at home, with clear instructions written down of how to manage the pain medication”.



Patient Journey Four: Discharge back to a Care Home

Communication between staff, carers and families at discharge

I requested that when mum was discharged, I would be contacted so that I could pick her up from hospital. I left my telephone number and contact details and was very disappointed that no one contacted me when she was discharged.

“My Mum left hospital with no discharge notes”.

I rang the hospital on the morning of her discharge, and they said that mum would probably be discharged after 1pm when the Doctor had done his ward rounds. The ward staff said they would contact me so that I could collect her from the ward and take her to the care home.

To my knowledge my mum was left waiting at the hospital for transport and no one could tell me where she was. Despite trying to find out, I still have no idea where she had been waiting for those ‘missing’ few hours. She did not arrive back at the care home until around 6pm despite being discharged after lunch time. Mum cannot speak and could not tell anyone if she had anything to eat or drink whilst she was waiting for transport by ambulance to the care home. If I had been contacted, I would have taken her myself and known that her needs had been met.

Support Services Post Discharge

The manager and staff at the home had to chase up the hospital and GP to find out if she needed any further treatment as no discharge notes were sent with her or made to available to the care home.

“To my knowledge my mum was left waiting at the hospital for transport and no one could tell me where she was”.

Patient Journey Five: Albert

Albert has been in Royal Blackburn Teaching Hospital (RBTH) twice last year (2018) because the first discharge resulted in a readmission. He has advanced dementia and requires a lot of support from his immediate family. Albert followed a Lancashire discharge pathway.

Following a fall and fracture, Albert's first two-week hospital stay was said to be 'a poor experience' on the fracture ward.


"As the main carer I was not kept informed about his progress whilst he was in hospital or involved in any discharge planning".

The only assessment that took place on the ward was to see if he had the ability to stand with a frame. There were no considerations about how he would cope at home and his dementia was not factored in at all. My needs were never considered, and I was not listened to or involved in the discharge planning. I was just asked if I could transport him home and was told that within a few hours of being home an assessment would be undertaken by 'Home First', who would tell me what care was needed.

"Where a patient is compromised with dementia the person involved in their day to day care 'should be fully involved in their discharge planning' according to the Dementia Action Alliance recommendations which forms the basis of the Dementia-Friendly Hospital Charter 2012 updated 2018".

We were not sign-posted to other organisations that could help us before leaving hospital.

The Home First assessment took place three hours after discharge. (The hospital bed is only kept open by the hospital for two hours after discharge.) Following a 30-minute assessment Albert was deemed to be able to cope on his own. I did not agree with this assessment as I knew he could not cope without a lot of support. In addition, he was left in a great deal of pain following the assessment because he had been discharged without any pain relief or prescription pain killers. I was not



given any instructions or advice on how to manage the pain or condition, so I resorted to giving him a pain killer which he already had at home, this was inadequate.

The first three days were very challenging as Albert had left hospital with double incontinence but no continence aids, so I had to keep washing him and changing his clothes. As soon as I left his home, I would get a call to come back, so I slept on the sofa overnight but was finding it difficult to cope.

The social worker contacted me three days after discharge and gave me a contact number for a carers support service but due to the excessive needs of looking after Albert and my family I did not get time to contact them once he was home.

I told the social worker that I could not cope with Albert's care needs. They advised me to contact the 'Crisis Team' (provided under the Lancashire pathway) for a daily visit in the morning. As Albert was doubly incontinent, I felt that this was totally inadequate, and I had to move into his home despite having my own family to look after and work. Eventually, I could no longer cope and after asking repeatedly for help, a carer from the crisis team was put in place to offer respite. It was then discovered that some medication he had been prescribed in hospital and sent home with had been causing the incontinence as they were for constipation. Once they were stopped so did the incontinence.

The carer from the crisis team identified that Albert's care needs were too much for care at home and called the social worker to review it and she also called the GP. This made a big difference as the social worker listened to the carer whereas they had not listened to me. Albert was asking to go back into hospital because it had been such a terrible experience coming home.

The GP visited, following the request from the carer and social worker, and was concerned about his discharge as no painkillers had been prescribed to take home which had severely affected his walking and ability to cope. Albert was also found to be dehydrated. The GP declared it a 'failed discharge' and wanted him to go back into hospital. As it was over three days the hospital bed had already gone, so Albert had to be readmitted to hospital by the GP where he was reassessed and transferred to Pendle Community Hospital (PCH) for reablement the same day.

No one would listen to my concerns prior to or after discharge. The incontinence could have been avoided if the medication had been reviewed and adjusted prior to

discharge. This added to the discharge home crisis. Continence aids would also have been helpful.

We felt that the social worker and Social Services had rushed the discharge, without adequate home care support in place. Carers were in place before Albert's fall and first admission to hospital, but his needs had been increasing. When he was discharged this support was no longer adequate and the family struggled for three days and nights until they got to crisis point and the GP reviewed the situation.

Second Hospital stay after a failed discharge

Albert stayed at Pendle Community Hospital (PCH) for three weeks where his pain was managed and there was more help and time for rehabilitation. The staff were dementia aware and he was better supported.

When he was ready to be discharged from PCH I stated that I could not cope with his care needs. I was given a leaflet with information to contact Memory Matters and that was it. We were very concerned because of the initial Home First discharge experience and wanted to consider discharge to a care home. Albert had stated that he wanted to go home but we did not believe that he had capacity to understand this fully in the long term, only what he feels in the moment. Again, the family and carers views were not considered, I was told by the hospital social worker quite abruptly that "it's not up to you!".

It took under 20 minutes for a member of staff to assess his capacity and he was declared fit to go home. As the main carer I again felt 'pushed away' from the decision making and felt I had no say in the discharge process. Albert's capacity is 'unreliable', he is not always fully aware of where he is so how could he have decided where he wanted to be? I felt like the decision had already been made without any considerations for me or the family's ability to cope.

The social worker was challenging and disrespectful to me when trying to decide what was best for my dad. I was told that, "If Albert goes into a care home it won't be your decision." They talked to Albert for about 20 minutes and think they know his needs. I have been caring for him for years and I know that what he is capable of is different from what he tells them he thinks he is capable of.

“Information gathered from support workers, carers, family and friends and advocates should be used to help create a complete picture of the person's capacity to make a specific decision and act on it”. (Nice Guidelines: NG108 Oct 2018)

By this time, I was so frustrated and exhausted I told the social worker that they would have to discharge him by ambulance as I felt that I could not drive him home. A home assessment was not completed for this discharge.

Once discharged home Albert was crying and asking to go back to PCH as he felt that he had made a mistake agreeing to come home. He was confused and thought PCH was a ‘holiday home’ and hadn’t realised he had been in hospital. I knew that different environments trigger different emotions but as soon as he was home, he became paranoid and felt scared. I contacted the social worker because I was concerned about the initial ‘capacity assessment’ undertaken by the hospital social worker prior to discharge on the first occasion. Within 24 hours of being home again the hospital bed had already gone and the social worker told me to ring 999 if I thought it was an emergency.

I eventually got through to the Crisis Team from the hospital and we got 48 hours crisis support which was extended for another 48 hours to find a care home. However, a change in home care provider and new carers did succeed in getting Albert to settle down. He started to attend a day centre which helped significantly. In fact, the day centre support reduced the need for Albert to go into a care home because it reduced his isolation and supported me as his carer. If this had been considered in the discharge planning, it could have reduced the stress and trauma caused to Albert, myself and my family.

I believe the assessment to determine his capacity to choose to go home was inadequate as it felt too short to make an informed decision and to understand the implications of coping at home.

As the Carer, my views and concerns based on my knowledge and experience of Albert were completely dismissed because the social worker said he had capacity to be able to make the decision to go home. We knew as a family that this was mainly in the moment as he was not able to make longer term decisions; Albert was affected by the place, time and situation. I think the capacity test should have been done at

home where he would have understood that he would be on his own or if he felt scared or experience paranoia due to the Alzheimer's.

“As the family we knew that Albert was not always fully aware of where he is so how could he have decided where he wanted to be?”

We were not happy with the discharge of Albert on either occasion and would have complained but we did not feel that we had “the time or energy to complain” as we were busy caring for Albert and looking after their own family and work commitments.

“It's not the individual people or professionals to blame, it's the system that diverts to certain pathways which do not always lead to good outcomes”.



Patient Journey Six: My Relative

My relative was at Royal Blackburn Hospital for a few days in 2018. They were transferred to Pendle Community Hospital for nine weeks for rehabilitation following their initial fall. (They followed a discharge to East Lancashire)

Preparation for discharge

During the last two weeks of rehabilitation conversations were had about their discharge and family were involved in the discharge process. We were given some practical advice about them walking with a frame but no information about support on discharge was offered.

Communication at discharge

The family were spoken to on odd occasions by various professionals. No discharge meeting was held collectively. A physiotherapist took my relative home first to assess if they could cope and the family then gave feedback after 48hrs. We were not made aware of what services could support us after discharge and we felt our needs were not considered.

Support services post discharge

On discharge from the hospital we found our relative had deteriorated because they had not given them their medication during their reablement whilst in hospital.

The social worker from the hospital organised the reablement team to come into the home for three weeks but this was not enough support. No other support was offered despite the family finding it difficult to cope post discharge. The GP said that they should not have been discharged but the hospital maintained that they were medically fit.

Coping Post Discharge

My relative did fall again, and the ambulance was called but they were not taken to hospital this time. The crisis team came for three days but they said they do not offer overnight care. As my relative was at risk of falling again a family member had to sleep overnight. My relative ended up being readmitted to hospital again because they were still in severe pain. Following the second stay in hospital my relative did improve greatly and got back on their feet. In fact, they were better than they had been for a long time.

“During the last two weeks of rehabilitation conversations were had about their discharge and family were involved in the discharge process. We were given some

practical advice about them walking with a frame but no information about support on discharge was offered”.

Appendix 3: Enter & View Reports

To view the Enter and View findings and the Trust’s response please read the Healthwatch BwD Enter & View report to Ward C5 Royal Blackburn Hospital. (https://www.healthwatchblackburnwithdarwin.co.uk/sites/default/files/wdc5_report.pdf)

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