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Russell George MS
Chair, Health, Social Care and Sport Committee
Welsh Parliament,
Cardiff Bay,
Cardiff
CF99 1SN

7 January 2022

Dear Chair,

I am writing to respond to your invitation to give evidence to the Health, Social Care and Sport's Committee Inquiry into hospital discharge in Wales. Alzheimer's Society Cymru firmly believes that this is a vital piece of work that, if managed correctly, can have an incredibly positive impact on the care received by people living with dementia.

As you may be aware, the Cross-Party Group on Dementia in Fifth Senedd undertook an inquiry on hospital care for people living with dementia, and we have included the full report with this submission for the Committee's attention. As Alzheimer's Society Cymru provide the secretariat for the Cross-Party Group, should the Committee like to work with the Cross-Party Group, please do not hesitate to contact us.

Alzheimer's Society Cymru is aware that the process of discharge and the discharge service is the final setting a person living with dementia and their carer and/or family will experience when receiving hospital care. Whether that is discharge to their own home, respite care, residential care, or a more specialised setting; ensuring the discharge process is thorough, smooth, well-communicated and timely is essential to providing continuous and excellent care.

On average, people with dementia spend nearly four times as long in hospital following a fall and the resulting frailty from a fall and an extended stay in hospital can increase the likelihood of them being unable to return home. A high standard of personalised care and effective communication between medical staff, families and other agencies will facilitate a more effective and efficient discharge for an individual patient.

Alzheimer's Society Cymru is aware that, prior to the Covid-19 pandemic, it is estimated that approximately 25% of beds in hospitals are occupied by people living with dementia. Their length of stay is often longer than for people without dementia and there can also be delays in supporting them to leave hospital; for unplanned hospital admissions:

- 36.4% of people living with dementia are discharged to a different residence and the readmission rate for people living with dementia is far higher than for people without - this is 8.2% vs 3.5% for elective care and 25% vs 17% for non-elective care.

During the evidence collection for the Cross-Party Group report on hospital care, we received over 2000 responses from individuals, organisations, health & social care staff, people living with

Mae'r Gymdeithas Alzheimer yn elusen gofrestredig yng Nghymru a Lloegr (296645) ac ar Ynys Manaw (1128)
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dementia, and paid & unpaid carers. Below are some of the most hard hitting and illustrative quotes we received during the evidence collecting process.

“Even when mum was meant to be being discharged, I was told that she would go home that afternoon or evening. I then got a call the next morning from her home to ask where she was, I believed she was with them so frantic calls were made only to find out that the hospital couldn’t get an ambulance and just kept her but didn’t bother to tell anyone, so she got no visitors that day.”

“The discharge system was our greatest bug bear. One Christmas Eve my mum rang me in a panic to say he was being discharged and she did not think she could cope as he was too poorly. I drove 12 miles to pick her up and when we got to the hospital the sister said they’d reassessed him and he couldn’t go home, and he didn’t for quite a while.”

“When care homes visited to do their assessment, they didn’t want to take the patient as a residential as they could see the level of care the patient would need, yet social services would not change their assessment to nursing needs, so discharged patients hang around in hospital using a bed they do not need waiting for a care home that will take them.”

“Their special needs were clearly not being addressed. The most troubled lady was to have been discharged, but appropriate provision could not be organised in the community. She was effectively “stuck” in hospital. Bad for her, bad for the other nearby patients.”

“Unfortunately, my mother was not discharged. She spent 13 weeks in hospital and her condition deteriorated drastically. She died after 13 weeks. She arrived in hospital being able to walk, eat independently but her condition, vascular dementia, took over.”

“Discharge took many weeks despite mum already having a care home place that she was fully funding - the only change required was from residential to nursing care. The discharge liaison nurse/social worker did not speak to me and made incorrect assumptions regarding getting council funding which delayed matters. I have guardianship and legal deputy - I should have been the decision maker - I was ignored until I made a fuss.”

It is worth noting that the fieldwork for this report was conducted between late 2018 and mid-2019, prior to the Covid-19 pandemic. It has become clear over the past 18 months that people living with dementia who are awaiting discharge from hospital have been hugely negatively impacted by the pandemic.

Both Betsi Cadwaladr and Cardiff & Vale Health Boards, alongside their respective Councils, have recently issued statements calling on unpaid carers to help with discharge of family members from hospitals in order to alleviate the issues being faced by hospitals and health boards across Wales. Alzheimer’s Society Cymru has also head anecdotal evidence of other health boards asking unpaid carers to take on care that should be being given by Local Authorities or paid carers, in order to help clear the discharge backlog in hospitals.

It is clear that this request has had a huge impact on unpaid carers, people living with dementia, and hospital staff themselves. Alongside the other impacts on people living with and affected by dementia throughout the pandemic; Wales has currently an estimated 1500 excess deaths of people living with dementia as a result of the pandemic; being 'stuck' in hospital is having incredibly negative effects on both the mental and physical health of people of people across Wales.

A lack of high quality, available social care is causing a serious backlog in discharge from hospital settings. Alzheimer's Society Cymru have heard stories from across Wales, since the pandemic, where people living with dementia have been ready to be discharged from hospital, but have been prevented by a lack of assessment, lack of places, or a lack of paid care staff to deliver care in residential settings. The story below comes from a supporter of Alzheimer's Society Cymru:

"My father went into hospital in May 2021, and he was sent from Wrexham Maelor to Chirk for physio due to a mobility issue. He was transferred at 11pm arrived at midnight, this was very distressing. Under 48 hours later, he was discharged with no care package. We asked the hospital staff if dad could go upstairs to access washing facilities and we asked if he was dry as he had experienced hospital incontinence. We found that he was not dry when he got into the car, and that he couldn't go upstairs, so he had to sleep on sofa. We were given nothing by the hospital. We couldn't get the spare beds downstairs, so dad had to sleep on a mattress or on the sofa.

"We believe that the hospital thought that he was disruptive at night, and that hospital did not do a safe discharge. Following his discharge, he had a critical care team for 12 days, then he moved into a care home, Hafod House, which was temporary until we could find appropriate care. Hafod House was a lovely home, and had great staff, but it was not suited to his needs. Dad has always been scared of going into a home and moving into Hafod put him in a distressed emotional state. This state never left him through his time at Hafod, so he started to get aggressive; we visited every day, but dad wanted to come home. The home called an ambulance on July 19th to have him taken to hospital. Dad sat all day with his bags packed waiting for the ambulance but by 7pm the ambulance hadn't arrived, and dad eventually left the home at 5am.

"Dad was always moved in the middle of night; this has led to unease and aggression from dad. Following the ambulance call, dad spent 24 hours in A&E again, which is not the correct place for him, due to the high risk of infection. Although dad is mentally calmer in a hospital and he recognizes the environment, his thought process is that this is temporary, and he will head back to his own home. The hospital wants to remove him to a care home and have previously threatened to do it without consent. As a family, we understand why the hospital want him removed but this will cause serious harm to my father's physical and mental health.

"My father has always been a quiet, non-confrontational person. But we firmly believe that his dementia is negatively affecting him, and the current situation is making it worse. As of January 2021, my father is still in hospital."

As can be seen in the story above, even when discharge happens, it is not always done correctly, for the benefit of the person living with dementia, to enable their care to carry on seamlessly from hospital to residential setting. This places incredible pressure on family members delivering unpaid care to ‘fill in the gaps,’ often at the expense of their mental, and sometimes physical health. This situation cannot be allowed to continue.

Alzheimer’s Society Cymru firmly believes that fixing the social care crisis will go a long way towards fixing the discharge crisis in Wales.

In the Cross-Party Group on Dementia report into hospital care, three solutions were proposed to be trialled and implemented across all wards and hospital care settings throughout Wales:

- Hospitals to trial set discharge slots for people living with dementia to enable the availability of care homes, carers, and family members to be fully involved in the discharge process. The Cross-Party Group believes that these slots should be between 9am and 11am and 4pm and 6pm.
- Ward staff to ensure that a multi-disciplinary team approach is taken to discharge planning, including working with social services, pharmacy, third sector organisations and transport services where appropriate.
- Discharge teams to ensure that care plans, medicines and transport are in place prior to discharge and that any documents are included in a ‘discharge folder’ to travel with the patient and shared with family, companion, carers, care homes, or community services.

As a result of the pandemic, and the ongoing issues being experienced by health boards, Alzheimer’s Society Cymru would like to add the following solutions to the three listed above:

- The Welsh Government to immediately provide ring fenced funding to ensure that recruitment gaps in social care are fulfilled. Without adequate provision for people leaving hospital, unbearable pressure will continue to build on unpaid carers, a group of people who have already been stretched to their limits across the pandemic.
- Prioritise those living with dementia in discharge planning and process in order to ensure that those who are most vulnerable in our society are supported to leave hospital and resume their lives.
- Ensure that paid care staff are paid a fair wage for their work, bringing pay scales in line with the NHS in order to ensure the recruitment gaps in social care are filled to enable better discharge planning and processes from hospitals to residential settings.

Alzheimer’s Society Cymru firmly believes that these six solutions will enable a smoother and more appropriate discharge to the setting most appropriate to meet the needs and wishes of the person living with dementia. We would encourage ward staff to begin discharge planning immediately on admittance of a person living with dementia to their ward. For example, should a patient with dementia be admitted for a hip replacement as a result of a fall, Alzheimer’s Society Cymru would like to see a discharge team put together during admittance.

This team would work on all aspects of a discharge, including medicines and physiotherapy, with a coordinator to ensure that all medication and support plans are collated to one place and shared with the patient and carers when a discharge is agreed, and that a discharge is made to the correct setting in timely fashion.

Alzheimer’s Society Cymru also believes that set discharge slots would make discharge process smoother and more efficient for both the person living with dementia and the carer or care home they are being discharged to. Dedicated discharge slots would enable improved planning and management for all those involved in the discharge process – for example care homes could provide staff to manage and accompany discharge, carers could plan to take time off work to collect and resettle relatives. All of this we believe would significantly improve the overall outcomes for people living with dementia in relation to their hospital experience.

Kind regards,

Sue Phelps
Country Director, Alzheimer’s Society Cymru

No understanding, no knowledge, no support

Hospital care in Wales

March 2021

Report from the Cross-Party Group on Dementia

Alzheimer's Society Cymru
Unedig Yn Erbyn Dementia
United Against Dementia

Foreword

People living with dementia are highly vulnerable within the hospital setting: their health can, on occasion, significantly and suddenly worsen during an admission and many of us living with a diagnosis and our loved ones would describe being very afraid of a hospital admission.

In a hospital setting there is a need for a more human aspect to the treatment of a person living with dementia, their families and carers. A stay or visit to a hospital setting requires the balance of many aspects of wellbeing. An imbalance of those aspects can result in a deterioration in health and even loss of life.

Yet up to half of all acute hospital beds in Wales are occupied by a person living with dementia at any one time, typically for a condition unrelated to their dementia. Whether an inpatient or outpatient, a person living with dementia brings their specific needs with them. Some social, some health needs and some specific to their diagnosis of dementia.

The care provided to inpatients living with dementia in acute hospitals is hugely variable. The experiences reflect the lack of appropriate staff training, and therefore understanding. Currently the needs of the organisation take priority over the needs of patients.

Whilst this report has focused specifically on people affected by dementia, many of the key messages are equally applicable to other people who need hospital care.

It is also relevant not just to our current generation of older people and their families, but to future generations and potentially each of us, as few can predict when we might need an admission to hospital in the years to come. It is in all our interests to rethink the impact of a hospital admission.

All aspects are underpinned by understanding, vital knowledge and compassion. An individual living with dementia should be treated with equal respect, expertise and attitude as any other individual, if not more.

Change is needed to improve the care for people living with dementia during an acute hospital admission.

Our thanks to the Welsh Assembly Cross-Party Group on Dementia and Alzheimer’s Society Cymru for producing this report.

Nigel Hullah, Ceri Higgins and Linda Willis
– living with, and affected by dementia.

Welcome to the report of the Welsh Assembly's Cross-Party Group on Dementia's inquiry into hospital care for people living with dementia in Wales. This report has taken 18 months of hard work, commitment and emotion to put together, and we hope that it contributes to shaping the future of hospital care for everyone living in Wales, regardless of a dementia diagnosis.

The solutions contained within this report are innovative, but we believe achievable with regards to implementation. With a £9million annual allocation from the National Dementia Action Plan (NDAP), funding is available to support and enable improvement across our hospitals in Wales. We look forward to working with Local Health Boards, Local Authorities and Regional Partnership Boards, alongside the Welsh Government and other key stakeholders, to put these solutions into practice so that people living with dementia benefit from much improved care during a hospital stay.

With more robust scrutiny of current spend by Welsh Government, we would be in a position to evidence that funding is being used to best effect but also to identify where any gaps and additional investment is required.

For too long, Wales has accepted a culture of valiant failure in dementia care, both in hospital and in social care. In addition, there has been increasing media coverage of care falling well short of what people have a right to expect and this should have acted as a 'wake-up' call for action. Lack of compassion, dignity and respect has resulted in a low expectation of people affected by dementia as to what constitutes excellent care. This is unacceptable, and whilst this report will offer some solutions in relation to improving standards of care, we cannot ignore that it will take a fundamental shift in culture at Government and leadership level within the NHS to support and drive forward change. By 2050, there will be 100,000 people living with dementia in Wales, placing an ever-greater stress on a system stretched to breaking point now. Alzheimer's Society Cymru and the Cross-Party Group on Dementia firmly believe that the will, and political drive to improve is there, and we hope this report, and its recommendations, are a first step in driving an agenda for change. We must unite across all sectors to fix dementia care.

Sue Phelps – Country Director,
Alzheimer's Society Cymru

To anyone who has ever visited a loved one living with dementia in hospital or had to take and collect them from hospital many of the challenges highlighted in this report will be familiar.

Dementia care in hospital is a particularly emotive element of living with and caring for a person with dementia.

As a Member of the Senedd, it is an issue that is close to my heart because unfortunately, I have heard too many stories of poor dementia care experiences in hospital.

Sadly, evidence gathered through this inquiry indicates that the required holistic approach to care of people with dementia in hospital is often sub-standard. The Covid-19 pandemic has further shone a light on the need for change.

We know that people living with dementia decline rapidly in hospital to the point of developing, at best, extra care needs, or at worst, never leaving hospital. People living with dementia often do not receive the person-centred care required to make a stay in hospital comfortable.

That is why as chair of the Cross-Party Group on Dementia, I am really pleased this report identifies constructive, realistic and practical solutions. Many of the solutions suggested are already in use in Wales or in other nations of the UK.

We firmly believe in the Cross-Party Group that these solutions are not only reasonable to implement but with the funding available through the National Dementia Action Plan are scalable across Wales.

With its ageing demographic Wales anticipates having at least 100,000 people living with dementia by 2050. This will inevitably place an increased stress on a system that is already under pressure.

That is why I would urge Welsh Government, Local Health Boards, Local Authorities and Regional Partnership Boards to look urgently at the solutions offered here to drive effective change.

I would like to finish by thanking those who shared their experiences with us in the pulling together of this report.

It is only by listening to those with lived experience that we will co-produce more dementia friendly approaches that will help create kinder, friendlier hospital environments for people living with dementia, their carers and families.

Lynne Neagle MS, Chair of the Senedd's
Cross-Party Group on Dementia

Executive Summary

Key Findings:

- 75% of respondents rated routine admissions as worse to average.
- 72% of respondents rated discharge as worse to average.
- 56% of respondents rated dementia knowledge of medical staff as average or worse.
- 54% of respondents rated the experience of Accident & Emergency (A&E) for people living with dementia as average or worse.
- Top areas for improvement are dementia knowledge of medical staff (52% rated number 1) and coordination of services (47% rated number 1)
- Despite admissions and discharge having 75% and 72% average or worse ratings, only 37% and 29% viewed these as the most important areas for improvement.
- 35% of respondents rated communications between wards as the top area for improvement.

Solutions:

Accident & Emergency:

- The creation of quiet spaces, away from main seating/waiting areas, where people living with dementia can wait on arrival at A&E.
- Fast tracking people living with dementia through to the appropriate setting for their care needs.

Care in the hospital:

- All hospitals to make greater use of their volunteer programmes, with a specific focus on providing support to patients living with dementia who are in a general ward setting.
- Wards to move away from condition related and task-based care towards a person centred, holistic approach.
- All wards to nominate a named person (with appropriate cover) who will be the liaison for the care of patients living with dementia, and can act as an information point for families, other wards and external agencies. Having more than one person will provide continuity.

Discharge:

- Hospitals to trial set discharge slots for people living with dementia. This will enable care homes, carers and family members to support, understand and contribute to the discharge process. Taking into account what people have told us, the Cross-Party Group believes that these slots should be between 9am and 11am and 4pm and 6pm.
- Ward staff to ensure that a multi-disciplinary team approach is taken to discharge planning, including working with social services, pharmacy, third sector organisations and transport services where appropriate.
- Discharge teams to ensure that care plans, medicines and transport are in place prior to discharge and that any documents are included in a 'discharge folder' to travel with the patient. Those who are caring for the patient onward from discharge should be kept fully informed.

Care across the hospital setting:

- The development of an approach to learning, development and training based on individual staff need rather than a 'blanket' approach designed to train all hospital and medical staff to a certain level.
- The development of a nationally recognised indicator of a diagnosis of dementia that can be placed on page one of a person's notes and carried across all settings to be accompanied by a one-page sheet detailing the individual's needs, like and dislikes.
- Full implementation and training for staff on 'John's Campaign' and the role that family and carers can play in delivering person centred, high quality care in a hospital setting.

Care Homes:

- Care homes to nominate a named person who will be the liaison for the care of patients living with dementia and can act as an information point for wards and care settings in hospitals. This person would work and develop relationships with the nominated persons on wards described earlier.
- All hospitals to work with care homes to draft joint working policies to allow care home staff, where appropriate to perform care functions on hospital sites, particularly for people living with dementia with high level of need.
- NHS Wales to provide insurance cover for any care assistant that accompanies a patient living with dementia during their hospital stay.

Dementia Friendly Hospital Charter:

- All hospitals to sign up to the Welsh Dementia Friendly Hospital Charter, with associated action plan for implementing improvement, and a robust process for monitoring.

Introduction

About the Cross-Party Group

The Cross-Party Group (CPG) on Dementia is a group of Welsh Assembly Members from all parties with an interest in dementia.

Chaired by Lynne Neagle AM (Labour, Torfaen) the Group meets four times a year in the Nationwal Assembly for Wales. It focuses on issues facing people affected by dementia in Wales, and shares knowledge and experience to make recommendations for improvements.

Background to the Inquiry

When a person living with dementia is admitted to hospital, they are often at their most vulnerable, and their health can deteriorate rapidly upon admission. Any unnecessarily lengthy inpatient stay in hospital can make it more likely for the person to lose their independent living skills such as toileting, dressing themselves and eating and drinking unassisted. A lack of understanding about dementia amongst medical staff can also have a significantly adverse effect on the experience of the person with dementia for both long and short stays in a hospital setting.

Welsh Government's Dementia Action Plan (NDAP) pledges to take action on improving hospital care for people living with dementia.

However, people living with dementia have told us that:

'It must have been absolutely traumatic for my dad – no understanding, no knowledge, no support. He couldn't communicate'.

– Carer of a person living with dementia

'Most of the nurses, especially in the general ward, just don't have a clue. They're just not getting the education on how to deal with people with dementia'.

– Person living with dementia

Started in October 2018, the Inquiry was launched by Alzheimer's Society Cymru at the request of Lynne Neagle AM, the Chair of the CPG. Evidence gathering started immediately, and due to an unanticipated level of interest, Alzheimer's Society Cymru agreed to extend this period until the end of January 2020.

COVID-19

Unfortunately, the COVID-19 pandemic delayed the completion and publication of this report from Spring of 2020 to Spring of 2021. The Cross-Party Group is aware that this means the research contained within is now two years old. However, we strongly believe that the COVID-19 pandemic has served to shine a light on the issues raised in the report and highlighted how vital it is that they are fixed.

We know that the majority of policy decisions going forward will be taken with a view to helping society, the health and social care sectors and other sectors to recover from the impact of COVID-19. We hope that this report will allow policy makers insight into the issues faced by people living with and affected by dementia prior to the pandemic, that have become exacerbated by COVID-19, and provide some solutions on how to improve the hospital experience.

Policy Context

As readers of this report will know, dementia is an issue that touches many either directly or indirectly, with dementia care in hospitals being a particularly difficult and emotive aspect of living with and caring for a person with dementia.

There have been numerous reports, investigations, and reviews into dementia care in hospitals prior to this, and each one has played its part in shaping the context of this report.

Reports such as the Older People's Commissioner for Wales 'Dignified Care?', published in 2011, which looked at the expectations of older people in Wales for their care in a hospital setting; what could be done to improve areas of poor practice; and how to drive positive change for anyone admitted to hospital.

Alongside reports such as 'Dignified Care?', reviews into incidents of poor practice, such as Tawel Fan, including the reports by Donna Ockendon and Betsi Cadwaladr Health Board; as well as the 'Trusted to Care' review of the Princess of Wales Hospital and Neath Port Talbot Hospital at Abertawe Bro Morgannwg University Health Board have fed into this report. These reviews have shone a light on the darkest areas and worst practice that we have seen in Wales. The solutions presented in this report will allow for the findings of these reviews to be consigned to history, as practice like this should never be allowed to take place in Welsh hospitals again.

Welsh Government policies were considered in the compilation of this report. The National Dementia Action Plan states "We expect health boards to ensure that their hospitals embed a clear rights-based approach to ensure that people living with dementia are treated with dignity and respect at all times."[1] The section titled "The Need for Increased Support" contains a significant number of references to hospital care, and the Inquiry has used these to inform suggested measurements for progress against the action plan.

This report also draws on wider Welsh Government policy, including 'A Healthier Wales.' The goals and aims of 'A Healthier Wales' will help people living with dementia, and affected by dementia to live longer lives, and live those lives as well as possible. These goals and aims are to be supported, and they have strongly influenced the work of the Cross-Party Group Inquiry, and the solutions offered in this report.

In producing this report the Cross-Party Group has also considered work undertaken by Welsh Assembly Committees, including the report of the Health, Social Care and Sport Committee into the use of anti-psychotic medication. This work has been vital for the Cross-Party Group to develop the nature and context of the inquiry and identify possible solutions.

Research undertaken by Dr Katie Featherstone at Cardiff University has greatly influenced the work undertaken by the Cross-Party Group. Dr Featherstone's research has been pivotal in shaping the work of this Inquiry, and her contribution to the field of dementia care should be noted.

The Inquiry has capitalised on work undertaken by the Royal Colleges and third sector organisations. This work includes the regular National Audit of Dementia carried out by the Royal College of Psychiatrists, the findings of which have been invaluable in providing a robust statistical base for the work undertaken by the Cross-Party Group. Also included in the background of this report is policy and public affairs activity undertaken by the Alzheimer's Society, including the 'Fix Dementia Care' campaign, and work undertaken in Wales in conjunction with the Welsh Language Commissioner on Welsh language in dementia.

Welsh Government's National Dementia Action Plan (NDAP) lays the foundation for the delivery of current and future dementia care in Wales. The five year Plan was co-produced with over 1000 people living with dementia and launched in February 2018. It lays the groundwork, and blueprint for all work done in Wales in the sphere of dementia care, and the Cross-Party Group believes that it should underpin the work of this inquiry. Threaded through the NDAP and the work of the Cross-Party Group are the 'Dementia Statements', one of which is:

> **'We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live'.**

The Statements reflect the rights that people living with dementia have and should receive through all aspects of their life, and they are especially pertinent when seen through the lens of hospital care.

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[1] *Dementia Action Plan for Wales – Welsh Government – page 25*

Methodology

In summer 2018, the Chair of the Cross-Party Group, Lynne Neagle AM (Labour, Torfaen) commissioned Alzheimer's Society Cymru to undertake an investigation into care received by people living with dementia in hospital. This was borne out of personal experience and concerns over standards of care.

The work was officially launched in October 2018, with a narrative survey designed to capture people's experiences of dementia care in hospital across Wales. This online survey was live from the launch of the Inquiry in October 2018 to 16 July 2019, receiving 306 responses.

In the early months of the online survey going live, the project team conducted four roundtable events attended by people living with dementia, their families and carers and professionals, and hosted by the elected members on the Cross-Party Group. The meetings were held in the following locations:

- Pontypool – Lynne Neagle MS
- Newport – Jayne Bryant MS
- Wrexham – Mark Isherwood MS
- Llangefni – Rhun ap Iorwerth MS

The results of this survey were analysed by the project team at Alzheimer's Society Cymru and were used to create a quantitative survey to enable the collection of data to provide statistical evidence for the Inquiry. The questions asked in this survey were focused on key areas identified in the narrative survey. These were:

- Dementia knowledge and understanding of medical staff.
- The experiences of Accident & Emergency for people living with dementia.
- Routine (non-emergency) admissions for people living with dementia.
- Discharge from hospital for people living with dementia.

The survey then asked respondents to tell us about specific experiences they wished to share. Finally, the survey asked respondents to rank six areas for improvement from 1 to 6, with 1 being the most important, and 6 being the least important. These were:

- Increasing the dementia knowledge and awareness of medical staff (nurses, doctors, health care assistants).
- Increasing the dementia knowledge and awareness of other hospital staff.
- Improving communication between different wards and care settings.
- Fast tracking admissions for people living with dementia.
- Creating set discharge slots for people living with dementia.
- Improving coordination of services (i.e., residential care facilities and hospital wards; social care and domiciliary care)

We then asked respondents to offer any other suggestions to improve dementia care in hospitals. We received 178 responses.

During the period, the surveys were open, the project team undertook a gap analysis in relation to where responses had been received. It was agreed that an effective way to engage more evidence in the geographic areas where we had received a low response rate was to hold a series of roadshows within hospitals. These events took place at 13 hospitals across Wales. These were:

- Bronglais Hospital, Aberystwyth
- Prince Charles Hospital, Merthyr Tydfil
- Glangwili Hospital, Carmarthen
- Royal Gwent Hospital, Newport
- Brecon Memorial Hospital, Brecon
- University Hospital Wales, Cardiff
- Ysbyty Gwynedd, Bangor
- Wrexham Maelor, Wrexham
- Singleton Hospital, Swansea
- Victoria Memorial, Welshpool
- Withybush Hospital, Haverfordwest
- Nevill Hall Hospital, Abergavenny
- Princess of Wales Hospital, Bridgend

These roadshow events comprised a stand in a public area of the hospital, and visits to clinic waiting areas, wards, and cafes to engage with the public, medical and hospital staff as well as ambulance and visiting social care employees and volunteers. Members of the public and hospital staff were asked if they had experience of dementia in either their personal or professional lives. These roadshow events used the same survey as the online quantitative survey in order to ensure that the evidence gathered was consistent. The hospital roadshows gathered a total of 1739 responses.

During the work, a gap was identified in the level of responses from care homes, an integral part of care provision for people living with dementia moving in and out of hospital. The project team worked with Age Cymru in order to design and promote a survey to target care homes and their staff. This survey, like the others, was hosted online, and issued to 257 care homes across Wales. We received a total of 24 responses.

The survey received a total of 2247 responses across all platforms.

Alongside the surveys, the project team hosted an email address to allow respondents to give greater detail in their responses, or to submit a written response to the project team. This email address received 54 responses and allowed for the capture of more detailed and personal anecdotal experience.

Finally, the Cross-Party Group held an evidence session with Dr. Katie Featherstone (Cardiff University), Valerie Billingham (Age Cymru) and Nicola Davies-Job and Lisa Turnbull (Royal College of Nursing). This session covered general questions to the entire panel, and then specific questions to the organisations and individuals on the panel.

Key Findings

- 75% of respondents rated routine admissions as average or worse.
- 72% of respondents rated discharge as average or worse.
- 56% of respondents rated Knowledge of medical staff as average or worse.
- 54% of respondents rated the experience of A&E for people living with dementia as average or worse.
- Top two areas for improvement are knowledge of medical staff (52% rated number 1) and co-ordination of services (47% rated number 1).
- Despite admissions and discharge having 75% and 72% average or worse ratings, only 37% and 29% viewed these as the most important areas for improvement.
- 35% of respondents rated comms between wards as the top area for improvement.

Accident and Emergency (A&E)

Often the first area of a hospital that people living with dementia interact with in a crisis, 54% of our survey respondents rated their experience of A&E as average or worse.

The evidence received by the Cross-Party Group, from a wide variety of respondents, indicated that A&E is often a last resort for people living with dementia and their carers and families. We heard distressing stories from carers and family members who, desperate for a break from caring, used A&E as a means of accessing respite. We have heard stories of care home staff being petrified to send residents to A&E.

"All staff that my mother came into contact within the general hospital and especially A&E had no idea how to approach a patient with dementia."

"The experience I had with my local A&E was truly distressing for the patient and myself, waited 11 hours 30 minutes before seeing a Doctor."

"When in A&E all staff treated my mother as a normal patient. I.e., considered that she understood all questions and was aware of what was happening. No consideration was given to her condition."

"We've spent more time in A&E than we would ever want to. We visit between two to three times a month and we constantly see elderly people with dementia distressed, alone, sitting on beds in cubicles or on gurneys in corridors."

"Following my own diagnosis of early onset Alzheimer's Dementia, I took ill with an unrelated health condition, an ambulance had to be called and following the paramedic's assessment, I was taken to A&E. I lay on a trolley in a corridor for approximately 8 hours, before receiving appropriate treatment and being admitted onto a ward. During most of that time in the corridor the patient in front of me, also lying on a trolley, was distressed and terrified. The lady in question was clearly suffering with dementia and spent hour after hour, crying and repeating that she wanted her husband (who was deceased). There was no way of reassuring her, nor giving the other waiting patients respite from her screaming."

"My dad broke his hip whilst in a care home and from that point everything went wrong with his care. Only after he was placed in the ambulance did it become obvious that my dad's femur was fractured. The hospital did not do a femoral block because the doctor in A&E couldn't and the on-call doctor refused to attend saying he'd do it once dad was on the ward (we didn't know this at the time). Dad was taken to X-ray back to A&E then onto a ward and moved to a bed without any pain relief, his screams, which we heard, were put down to his dementia."

We have heard that visits to A&E are upsetting and stressful experiences for both people living with dementia and their family and carers. They were faced with issues such as lack of knowledge and understanding of dementia; waiting times; availability of beds or comfortable seating; and the noise of the department all being factors that contribute to the unsuitability of the busy A&E environment for people living with dementia.

It is clear from the evidence we have gathered, that, although there are of good practice and good quality care in A&E, it is an area that causes substantial distress for people living with dementia, and one where clear, and significant improvement is required in order to ensure that the experience of A&E for people affected by dementia improves.

Therefore, the Cross-Party Group on Dementia calls for the following solutions to be trialled and implemented across all A&E departments throughout Wales:

- The creation of quiet spaces, away from main seating/waiting areas, where people living with dementia can wait on arrival at A&E.
- Fast tracking people living with dementia through to the appropriate setting for their care needs e.g., radiology, triage, wards.

The Cross-Party Group on Dementia firmly believes that ensuring people living with dementia have a quiet, calming space where they can wait for assessment and treatment, with a family member, carer or companion will enable better support and care. This will allow for information to be given in an environment where the appropriate time and attention can be given to the person living with dementia and that any communication is understood and accepted without distraction.

The Cross-Party Group on Dementia also believes that a person living with dementia should be fast tracked from A&E to their next care setting, such as X-Ray or a ward. This will minimise the time spent in an overwhelming environment, pain management can start sooner, and the appropriate assessment and diagnosis can be carried out. It will also allow medical professionals to mitigate against any additional impacts the injuries or illness may have on the patient, as well as minimise the negative effects that an elongated time in a busy and noisy A&E department could have.

Care on the hospital ward

Once a person living with dementia has been admitted to a ward, they are then faced with surroundings that can be disorientating and frightening which can increase their confusion. Hospital wards can be an unfamiliar and noisy environment and the person may not understand where they are and why they are there. Whilst there is faith and trust in medical and nursing staff to provide the care required, they may not necessarily know whether someone has dementia, or may lack experience of working with people with dementia. It is important that all staff are aware of a person's dementia as it may affect the type or nature of any treatment they receive. Knowledge and understanding of dementia, as well as what constitutes a person-centred, holistic approach to care will significantly improve an individual's well-being, their response to treatment, and enable a safe and timely discharge.

Unfortunately, evidence gathered through the Inquiry indicates that the required holistic approach to care of people with dementia in hospital is sub-standard. People reported a lack of person-centred care and poor standards of comfort on the ward. In addition, we have captured experiences that evidence people living with dementia decline rapidly in hospital where they develop additional care needs that can prevent timely discharge.

Our evidence also shows that time and workforce pressures are a key factor in the provision and standard of care provided in hospital wards. The Royal College of Nursing stated:

"Pressures on staff are intense, and although Wales doesn't publish data on nursing vacancies, the RCN estimates that there at least 1,612 [2] ***nursing vacancies in Wales today. Every week the additional hours put in by existing nurses equates to another 1000 hours' worth of work. Wales also spends an extraordinary amount on agency nurses. This is the biggest barrier to high quality care".***

The evidence gathered by our qualitative survey showed that coordination of services ranked the second highest of all suggestions for improvement, with 47% of respondents ranking it at the number one area for improvement. 35% of respondents also rated communications between wards and setting as the top area for improvement.

"I explained on many occasions to the ward she was admitted to that Mom wasn't allowed to be left alone, ever, as she was a full-time resident at a secure care home for dementia. I wasn't listened to."

"I currently work as a nurse on a dementia ward at the hospital and have spent the last 2 years working in a dementia nursing home. Whilst working at the home I have noticed major differences in the care given to patients with dementia. The home is completely dementia friendly and is adapted to meet their needs and although this isn't always as easy to input in hospitals the quality of care given in hospitals is disgraceful. However, the current ward where I work in a different hospital is amazing with the dementia patients offering crafts, entertainment, afternoon tea, a conservatory and garden. It is like home from home."

"In the ward they were most unhelpful and did not appear to know anything of the Hospital policies with regard to carers rights e.g., to visit at any time, to feed etc. They merely said, " He will have to go into a home". His carer insisted on tests to discount TIAQ/stroke, and on speaking with the doctor. "They did not screen him from others and failed to put him in pyjamas to preserve his dignity as he used incontinence pads. I only found out that there were hospital policies when I complained."

"He was provided with a bed on an acute admissions ward which was severely stretched and whose staff had no time to understand dad's illness - so much so he managed to get off the ward during the night. He was found wandering the corridors - and it was a fellow patient who informed us of this event."

"When you get to hospital medical staff work around you not with you leading to distress and sometimes aggression in the patient. Having diagnosed the problem and when sent to a ward often questions are fired at the patient and too little time given for response. Food is left on the bed tray and no regard taken as to whether the patient can feed themselves or needs to be prompted to eat resulting in staff deciding the patient does not want the meal. The same happens with drinks."

"My father was a patient on Sycamore Ward at St Woolos Hospital it was the best place for him to be to have his needs assessed and ability to access specialist social workers, Occupational Therapists etc. I dreaded the occasions when my father needed to be transferred to the Royal Gwent despite a member of Sycamore Ward accompanying most of the time it was apparent the patients were not well received and those staff with my father would always have to go and ask for help with turning, changing etc."

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[2] *RCN Wales – "RCN Wales report reveals that every week nurses in Wales work overtime equivalent to the value of 926 full-time nurses"*

The Cross-Party Group on Dementia calls for the following solutions to be trialled and implemented across all wards and hospital care settings throughout Wales:

- All hospitals to make greater use of volunteer programmes, and allow family, carers, and volunteers to support to patients living with dementia who are in a general ward setting.
- Wards to move away from condition focused and task-based care towards a person centred, holistic approach to care.
- All wards to nominate at least one named person who will be the liaison for the care of patients living with dementia, and can act as an information point for families, other wards, and external agencies.

The Cross-Party Group on Dementia firmly believes that having named persons on each ward shift would enable a greater level of accountability in the care provided to people living with dementia on the ward as well as support improved channels of communication. Carers, families and care home staff would have an identified individual with whom they can build a trusting relationship and share information. In addition there would be the opportunity for the named person to develop greater skills and knowledge in providing personalised care for people living with dementia.

The Cross-Party Group also believes that making greater use of volunteers, with thorough training on basic dementia care as well as fully implementing John's Campaign will allow more time for nursing staff to devote to delivering medical care to the best of their ability. It will also facilitate a move away from 'task oriented' care, towards a more person-centred individualised approach.

Discharge

The process of discharge and the discharge service is the final setting a person living with dementia and their carer and/or family will experience. Whether that is discharge to their own home, respite care, residential care, or a more specialised setting. Ensuring the discharge process is thorough, smooth, well- communicated and timely is essential to providing continuous and excellent care. On average, people with dementia spend nearly four times as long in hospital following a fall and the resulting frailty from a fall and an extended stay in hospital can increase the likelihood of them being unable to return home. A high standard of personalised care and effective communication between medical staff, families and other agencies will facilitate a more effective and efficient discharge for an individual patient.

The Cross-Party Group on Dementia is aware that it is estimated that approximately 25% of beds in hospitals are occupied by people living with dementia. Their length of stay is often longer than for people without dementia and there can also be delays in supporting them to leave hospital; for unplanned hospital admissions, 36.4% of people living with dementia are discharged to a different residence and the readmission rate for people living with dementia is far higher than for people without, 8.2% vs 3.5% for elective care and 25% vs 17% for non-elective care.

"Even when mum was meant to be being discharged, I was told that she would go home that afternoon/ evening. I then got a call the next morning from her home to ask where she was, I believed she was with them so frantic calls were made only to find out that the hospital couldn't get an ambulance and just kept her but didn't bother to tell anyone, so she got no visitors that day."

"The discharge system was our greatest bug bear. One Christmas Eve my mum rang me in a panic to say he was being discharged and she did not think she could cope as he was too poorly. I drove 12 miles to pick her up and when we got to the hospital the sister said they'd reassessed him and he couldn't go home and he didn't for quite a while."

"When care homes visited to do their assessment, they didn't want to take the patient as a residential as would see the level of care they would need, yet social services would not change their assessment to nursing needs, So Discharged patients hang around in hospital using a bed they do not need waiting for a care home that will take them."

"Their special needs were clearly not being addressed. The most troubled lady was to have been discharged, but appropriate provision could not be organised in the community. She was effectively "stuck" in hospital. Bad for her, bad for the other nearby patients."

"Unfortunately, my mother was not discharged. She spent 13 weeks in hospital and her condition deteriorated drastically. She died after 13 weeks. She arrived in hospital being able to walk, eat independently but her condition, vascular dementia, took over."

"Discharge took many weeks despite mum already having a care home place that she was fully funding - the only change required was from residential to nursing care. The discharge liaison nurse/social worker did not speak to me and made incorrect assumptions regarding getting council funding which delayed matters. I have guardianship / legal deputy - I should have been the decision maker - I was ignored until I made a fuss."

The Cross-Party Group on Dementia calls for the following solutions to be trialled and implemented across all wards and hospital care settings throughout Wales:

- Hospitals to trial set discharge slots for people living with dementia to enable the availability of care homes, carers, and family members to be fully involved in the discharge process. The Cross-Party Group believes that these slots should be between 9am and 11am and 4pm and 6pm.
- Ward staff to ensure that a multi-disciplinary team approach is taken to discharge planning, including working with social services, pharmacy, third sector organisations and transport services where appropriate.
- Discharge teams to ensure that care plans, medicines and transport are in place prior to discharge and that any documents are included in a 'discharge folder' to travel with the patient and shared with family, companion, carers, care homes, or community services.

The Cross-Party Group on Dementia firmly believes that these three solutions will enable a smoother and more appropriate discharge to the setting most appropriate to meet the needs and wishes of the person living with dementia. We would encourage ward staff to begin discharge planning immediately on admittance of a person living with dementia to their ward. For example, should a patient with dementia be admitted for a hip replacement, the Cross-Party Group would like to see a discharge team put together during admittance. This team would work on all aspects of a discharge, including medicines and physiotherapy, with a coordinator to ensure that all medication and support plans are collated to one place and shared with the patient and carers when a discharge is agreed, and that a discharge is made to the correct setting in timely fashion.

The Cross-Party Group also believes that set discharge slots would make discharge process more smooth and efficient for both the person living with dementia and the carer or care home they are being discharged to. Dedicated discharge slots would enable improved planning and management for all those involved in the discharge process – for example care homes could provide staff to manage and accompany discharge, carers could plan to take time off work to collect and resettle relatives. All of this we believe would significantly improve the overall outcomes for people living with dementia in relation to their hospital experience.

Care across the hospital setting

During the work undertaken as part of this Inquiry, issues were raised that do not fit neatly into the care settings already referred to, but instead across all care settings in a hospital. Whilst the obvious issues such as funding were raised, other issues that have come to light include the knowledge of medical staff, knowledge of other auxiliary hospital staff, the roll out of 'John's Campaign,' the roll out of the 'Butterfly Scheme' and how ward staff are identifying patients living with dementia in general settings.

Online or computer-based training is not necessarily the most effective method for delivering high quality, impactful dementia understanding. For the best outcome training should be practical and preferably including the involvement and input of someone who has lived experience of dementia.

The evidence we have collected shows there is a large disparity in how patients and carers view the knowledge of medical staff as opposed to the medical staff themselves. Overwhelmingly, patients and carers said medical staff knowledge was 'extremely poor', 'poor', or 'average' whilst medical staff have said that their knowledge is 'average', 'good', or 'excellent'. We have also heard evidence that shows people living with dementia are more likely to tell other hospital staff if they are experiencing problems, as they do not want to 'inconvenience' or 'worry' the medical staff assigned to care for them. We are concerned that these staff do not have the required knowledge to deal with these comments and issues, and that this is leading to further negative experiences and rapid deterioration of people living with dementia in hospital.

The Cross-Party Group on Dementia believes the low level in dementia knowledge and understanding across the range of hospital staff negatively impacts on a patient living with dementia throughout their stay in hospital, as well as impacting on their carers and families. The Group therefore calls for this to be addressed as a matter of priority, if patients and carers are to safely navigate the hospital journey. 54% of respondents to the survey said that improving the knowledge of medical staff is the most pressing issue to be fixed, whilst 32% said improving the knowledge of other hospital staff was the most pressing.

"Getting mum onto a ward that was in anyway suited to care for her was a nightmare, a real nightmare. We had to row, argue, shout and be threatened by nursing staff who would not allow us to stay with her as carers. But they were unwilling or unable to give the level of care she needed."

"Family were not encouraged to stay and help, e.g., at mealtimes, when large portions of sloppy food were left on the overbed table, often out of reach."

"Knowledge is poor, on the occasions mom was admitted for various infections/ injuries she had cot sides on the bed- a lidded beaker to drink from- neither of which was necessary at that time. Her mobility declined and we organised physio as we wanted her home ASAP as we could see her losing basic skills."

"Staff were not interested in the dementia patients they are not trained to look after them."

"Lack of knowledge and understanding seems to be a big problem so let's hope that by speaking out care can only get better."

"I am sorry to say that they appear to know very little."

"General medics and nurses seem to have little insight into the issues affecting people living with dementia."

"The care in admissions was fine, dedicated nurse put the butterfly symbol on the notice board and advised about discounted parking and stated that I could stay with my wife for as long as I needed. When transferred to the ward, the butterfly, although promised did not appear."

Therefore, the Cross-Party Group on Dementia calls for the following solutions to be trialled and implemented across all wards and hospital care settings throughout Wales:

- The development of an approach to training based on individual staff need rather than a 'blanket' approach designed to train all medical staff to a certain level.
- The development of a nationally recognised indicator of a diagnosis of dementia that can be placed on page one of a person's notes and carried across all settings, to be accompanied by a one-page sheet detailing individual needs, like and dislikes.
- Full implementation and training for staff on 'John's Campaign' and the role that family and carers can play in delivering excellent care in a hospital setting.

The Cross-Party Group on Dementia firmly believes that these solutions will lead to an improvement in the standard of care for people living with dementia right across the hospital settings. We understand how difficult it must be for porters, administrators and café staff or cleaners to engage in conversations and be given information relating to an individual's personal circumstances and medical care, especially if they are unaware of who to pass this onto. Allowing these staff to access in depth dementia training, to include signposting skills to medical staff and to other organisations will increase the opportunities to provide excellent care, and will create a safer, kinder, friendlier hospital environment for people living with dementia and their carers and families.

The Cross-Party Group also believes that the creation of a nationally recognised indicator of a dementia diagnosis, to be placed on all patient notes, records and medical passports will allow for a swift recognition of relevant issues, allow staff to implement the training they have received, and alert them to key information about the patient required to ensure that their care is person centred and delivered to the best of the staff's ability.

Finally, as this report has already mentioned, there is huge potential to positively improve the care of people living with dementia by using non-NHS staff in a hospital setting. We strongly believe that the quality of care would be improved if residential and nursing care home staff were allowed, empowered and enabled, to perform care functions for their patients in hospital care settings. Not only would this allow for one-to-one care, with people who are knowledgeable about the patient, it would free up nursing time to provide care, and complete tasks that are necessary for the care of other patients on the ward.

Care Homes

During the Inquiry, the project team identified a gap regarding the views of care homes on care for their residents when in hospital. As is discussed earlier in this report, a special survey was designed and developed in collaboration with Age Cymru to seek the views of care homes on the care for their residents when in hospital. Whilst many of the issues raised in this survey were the same as those raised across the rest of the work, there are specific nuances which deserve their own solutions.

Care homes across Wales have told us:

"When a resident goes to A&E via ambulance, we always send copies of their care plans, details of next kin and contact numbers, copies of medication records. 9 times out of 10 we have phone calls from A&E staff asking for information which has already been sent to them. If the resident is then admitted to a ward, we have the ward staff phoning to ask for all of the information again."

"Dementia Patients that have gone to A & E being returned to the home during the early hours of the morning without ringing through to let staff know."

"Hospital staff being unable to cope with behaviours associated with advanced dementia, requesting care staff to be present 24/7 which we care homes can't facilitate."

"On discharges the correct assessments are often missed and wards need to be asked to complete the required assessments".

"It is so poor that we send staff to the ward to ensure the basics: - Teeth in, hearing aid in, glasses clean and on, clean underwear and pads where required. Drinks put where they can reach them, assistance with feeding and a suitable choice of meal that they can manage. We frequently visit and these basics are not in place."

"[We would like] to work as a team to get the better outcomes."

"Respect is all we would ask as we respect other professions."

"Please ensure that the transfer information stays with the patient as they are moved between departments... Ensure a copy of the discharge summary comes to the home."

The Cross-Party Group on Dementia calls for the following solutions to be trialled and implemented across care homes and hospitals throughout Wales to improve the relationship between settings:

- Care homes to nominate a named person who will be the liaison for the care of patients living with dementia whilst in hospital and can act as an information point for wards and care settings in hospitals. This person would work, and develop relationships, with the nominated persons on wards, clinics, and other departments, as described earlier.
- All hospitals to work with care homes to draft joint working policies to allow care home staff, where appropriate to perform care functions on hospital sites, particularly for people living with dementia with high needs.

The Cross-Party Group on Dementia strongly believes that care homes provide an invaluable service in dementia care, and their input, knowledge and skills are crucial to ensuring that people living with dementia receive excellent care across all settings, both within the hospital and in the community. It is therefore vital that these experiences, knowledge, and skills are included in planning and management of care for their residents when they move into a hospital setting. The Group believes that the proposed solutions will allow for care home staff to be respected, listened to and involved in all aspects of their resident's care, thus contributing to more a integrated and person-centred pathway.

Dementia Friendly Hospital Charter

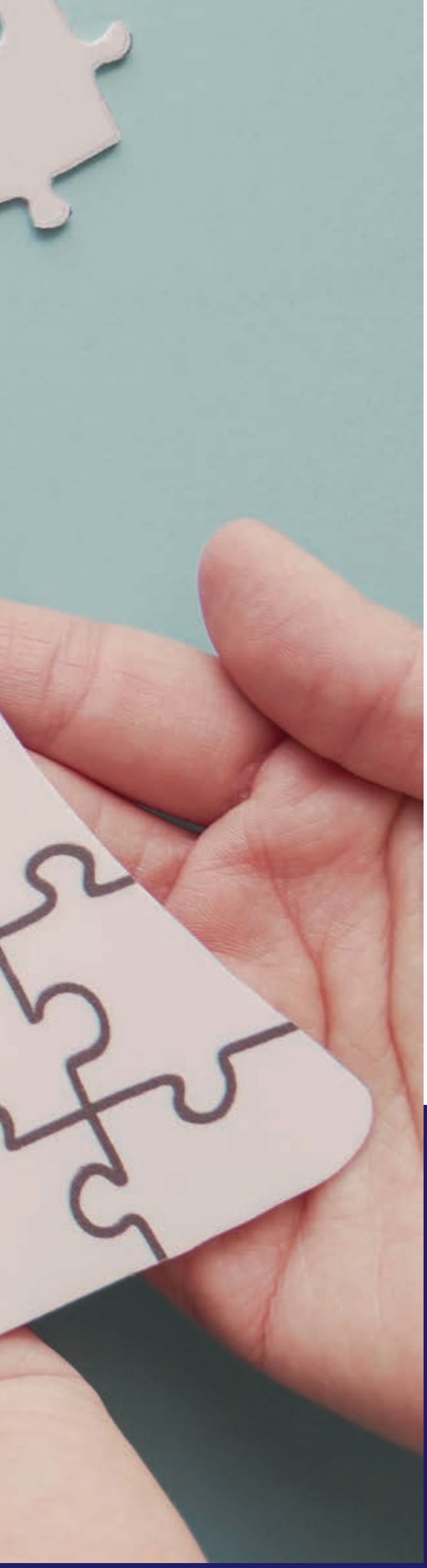
In 2015, the National Dementia Action Alliance (NDAA) launched the Dementia Friendly Hospital Charter in England. This charter has been designed in conjunction with the NHS Trusts in England in order to help them work towards becoming dementia friendly. The charter was revised in 2018. In 2019, work began in Wales between the NDAA, Alzheimer's Society Cymru, and Improvement Cymru, alongside the Health Boards and other partners to bring this charter to Wales and to create a version applicable to the specific needs and requirements of the Local Health Boards in Wales.

The work of the group developing the Welsh Charter is very closely aligned with the work of the Cross-Party Group on Dementia, and as such, the Cross-Party Group would seek to endorse the Charter on its launch in late 2020.

Therefore, the Cross-Party Group on Dementia calls for the following solution to be implemented across Wales:

- All hospitals to sign up to the Welsh Dementia Friendly Hospital Charter on launch in late 2020.

Conclusion



This report barely scratches the surface with regards to the significant issues surrounding all aspects of hospital care for people living with dementia in Wales. The Inquiry team received a multitude of evidence, and this report could have been extended to hundreds of pages. Instead, the Cross-Party Group team has decided to focus on the key areas contained within the final report.

A conscious decision was made to avoid commenting on areas to fix wider issues and problems in hospital care in Wales. These would include how we fill the 1500 nursing vacancies, implementation of the Nurse Staffing Levels (Wales) Act 2016, and work to create parity of esteem for social care workers and work to properly fund social care in Wales.

Instead, we have presented attainable and achievable short-term solutions designed to improve standards hospital care for people living with dementia whilst not ignoring the outstanding long-term issues highlighted. The Cross-Party Group on Dementia firmly believes that the solutions offered are not only reasonable to implement, but with the funding available through the National Dementia Action Plan and a shift towards a more dementia friendly culture, are scalable across Wales.

We also strongly believe that the solutions suggested are already in use in some parts Wales as well as in the other nations of the United Kingdom. We strongly urge health commissioners and practitioners to work with colleagues across health boards and in other nations to share best practice and develop tools that will allow them to deliver the best care possible for people living with dementia. We also urge that this collaboration extends to the social care sector, and carers, both paid and unpaid, who know the person they are caring for the best.

We urge Welsh Government to demand immediate action to be implemented across hospitals in Wales.

For too long, Wales has accepted a culture of valiant failure in dementia care, both in hospital and in social care. This cannot be allowed to continue. With an ageing demographic by 2050, there will be at least 100,000 people living with dementia in Wales. This will inevitably place an increased stress on a system that is currently stretched to breaking point. Alzheimer’s Society Cymru and the Cross-Party Group on Dementia firmly believe that there is a will, and political drive to make change.
We believe this report, and its solutions, offer a first step in driving that change.

We must fix dementia care.

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

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