



'Dignified Care?'

The experiences of
older people in hospital
in Wales

Executive Summary



Older People's Commissioner for Wales
Comisiynydd Pobl Hŷn Cymru

Introduction

Reflections on the Review

Ruth Marks, Older People's Commissioner for Wales

I consider that my Review has highlighted that the treatment of some older people in Welsh hospitals is shamefully inadequate. Organisations must do more to learn from those who are doing things well.

Fundamental change is needed. Patients need to know what quality care is, and staff need to be supported by systems and resources to empower them to meet patient's expectations. Poor practice should not be tolerated. The attitudes, behaviour and emotional intelligence of staff on the wards are crucial. We need strong, positive leadership at all levels and a system which builds in dignity and respect as the cornerstone of high quality care.

There are examples of effective leadership and good practice and it is vital these are built on and become regular practice. There is evidence that efforts to improve standards of care are making a difference and we should take encouragement and learn from this. They demonstrate what is possible and should play a key part in bringing about wider change.

Dame Deirdre Hine, Chair, Panel of Inquiry

It is imperative that the dignity and respect with which older patients are treated is at the forefront of the minds of all who manage and staff our hospitals in Wales. Attitudes and practices that assault the dignity and self esteem of older people at a time when they are most anxious and vulnerable must be stopped.



Panel of Inquiry (from left): Meg Edwards, Monty Graham, Dame Deirdre Hine (Chair), Meirion Hughes, Nicky Hayes and Dr Charles Twining.

Why the Commissioner conducted the Review

The Older People's Commissioner for Wales took up her post in April 2008 as the independent statutory advocate for people aged over 60 in Wales.

The law establishing the Commissioner's post, the Commissioner for Older People (Wales) Act 2006, provides the Commissioner with a range of legal powers, and an obligation to listen to the views of older people. The Commissioner is conducting this review under Section 3 of Commissioner for Older People (Wales) Act, which allows the Commissioner to review the effect on older people of how Welsh public bodies and providers deliver their functions. The report is produced under the Commissioner for Older People (Wales) regulations.¹

The Commissioner has travelled across Wales, listening to the experiences and views of older people from a wide range of backgrounds and communities to help her decide where she should focus her attention. Common themes have emerged in the Commissioner's discussions with older people, including whether older people are treated with dignity and respect, particularly when they are receiving hospital care.

This led to the Commissioner's announcement in March 2010 that the Review would focus on dignity and respect for older people in hospitals in Wales.

Older people are at the heart of everything that we do

The Commissioner is unique in the way in which she undertakes her work as an independent statutory advocate, because her priorities centre on the aspirations and experiences of older people. This distinguishes the Commissioner from all other Regulators and Ombudsmen.

The United Nations Principles for Older Persons of independence, participation, care, self-fulfilment, and dignity underpin all the Commissioner's work.

NOTE:

1. Commissioner for Older People in Wales Regulations 2007, Reg. 14(2) (2007/398).

Introduction

The remit of the Review

The Commissioner decided this Review would focus on hospital inpatient care because of the strength of concerns expressed about the impact on older people of a poor hospital experience.

An ICM Poll² of 1,500 people of all ages, commissioned by the Older People's Commissioner for Wales found that only 36% of people were confident that an older person would be treated with dignity in hospital. 31% of those polled were not confident an older person would be treated with dignity.

Overall 49% of people said that they, or an older person they know, had a positive experience of care in a hospital setting. 21% said they, or an older person they know, had a negative experience.

The Commissioner was also aware that people aged over 60, are significant users of hospitals in Wales, accounting for 47% of inpatient admissions in 2009 and 2010.³ She focused her Review on the experiences of older people who were, or had been, hospital inpatients for at least five days within the previous two years. This reflected concerns about the long term impact of a loss of dignity and respect during lengthier stays in hospital, rather than during shorter periods, such as in an emergency or outpatients setting. There were over 228,000 cases where an older person spent five or more days in hospital between January 2008 and December 2009.⁴

The recent structural reforms in the health service in Wales also presented real opportunities to influence change. All the newly formed Local Health Boards and one NHS Trust were subject to this Review: Aneurin Bevan Health Board, Abertawe Bro Morgannwg University Health Board, Betsi Cadwaladr University Health Board, Cardiff and Vale University Health Board, Cwm Taf Health Board, Hywel Dda Health Board, Powys Teaching Health Board and Velindre NHS Trust. Throughout the report they are collectively referred to as the "Health Boards and the Trust".

NOTES:

2. Ref: ICM interviewed a sample of 1000 adults in Wales aged 65+ by telephone between 18 - 25 March, 2010. A further 500 adults aged 18-64 were interviewed 14 - 19 April 2010.
3. Patient episode database for Wales: date of extraction by Health Solutions Wales 07/02/11
4. Patient episode database for Wales: date of extraction by Health Solutions Wales 28/06/10

Defining dignity

To define the elements of care which impact on dignity, the Commissioner used the framework set out by Help the Aged's report *The Challenge of Dignity in Care: Upholding the rights of the individual*.⁵

This identifies personal hygiene, eating and nutrition, privacy, communication, pain, autonomy, personal care, end of life, and social inclusion.

Methodology

To secure a robust and detailed evidence base from which to frame recommendations, the Commissioner appointed a Panel of Inquiry to collect evidence of older people's experience in hospital and to identify good practice.

The Panel, chaired by Dame Deirdre Hine, began its work in June 2010. The Panel issued a call for evidence to the general public in the summer of 2010. In particular, the Panel sought the direct experiences of older patients, former patients, and evidence from family members, carers, and organisations. The Panel received over 180 responses, with over 160 coming from individuals.

To supplement the evidence, the Panel decided to undertake a series of visits to hospitals within each Board and Trust area. During these visits to general and acute wards, the Panel sought the views of patients, their visitors, and key staff. The Panel also invited a range of organisations to meet them.

In January 2011, the Panel presented the Commissioner with their findings. The Commissioner has based her recommendations on their evidence.

Both the Panel and the Commissioner would like to thank those individuals and organisations who provided evidence. They would also like to thank patients, relatives, carers and staff who assisted during hospital visits, and those who helped the Panel analyse its findings.

NOTE:

5. Levenson R (2007) *The Challenge of Dignity in Care: Upholding the Rights of the Individual* London: Help the Aged

Recommendations

Commissioner's Recommendations

The twelve recommendations made in this report have been developed based on the findings of the Panel of Inquiry. A summary of the relevant evidence precedes each detailed recommendation.

Changing the culture of caring for older people in Welsh hospitals

1

Stronger ward leadership is needed to foster a culture of dignity and respect

Making dignity and respect a reality for all older people has to mean the consistent translation of the policies and principles of person centred care into actual good practice at ward level. For all staff, training is key, as is learning from good role models who are delivering dignity and respect. The Panel found that the best examples of excellent care were being delivered in settings where skilled ward managers were demonstrating strong leadership and were equipped with the knowledge and authority to shape the culture on their wards.

Detail of Recommendation 1

Health Boards and the Trust should ensure that the ward managers on every ward in which older people are treated are empowered with the skills and authority to create a culture of dignity and respect. This must include the:

- **necessary clinical leadership skills;**
- **support of specialist consultant nurses especially in dementia care and continence;**
- **knowledge of the correct staff numbers for their ward;**
- **authority to select staff;**
- **authority to ensure that their training needs are met; and**
- **responsibility for regular appraisal of the skills, knowledge and attitude of the ward staff.**

2

Better knowledge of the needs of older people with dementia is needed, together with improved communication, training, support and standards of care

The Panel found that there was general agreement amongst staff that a great deal more needs to be done to improve care for people with dementia. In both acute and community hospitals, concerns were raised about a lack of knowledge of the needs of people with dementia, the levels of training and support available, communications, and standards of care.

For people with dementia, admission to hospital can be a frightening and disorientating experience, and can lead to disturbed behaviour, greater risk of falls and increased use of sedation. The impact on patients, with or without dementia, being cared for on the same wards can be increased anxiety and distress.

There needs to be much clearer recognition that people with dementia are not an isolated group who somehow sit outside the mainstream of those receiving hospital care; rather, they should be recognised as a significant and increasing group within the hospital population whose care should be proportionate to their needs.

Health Boards and the Trust need to have a focus on service planning, delivery and review.

They also need to attend to the physical environment and staff learning and development. Regular contact and mentoring on the ward from dementia specialist staff is needed.

Recommendations

Detail of Recommendation 2

Regular dementia awareness training and skills development should be a requirement for all staff caring for older people. Specialist and skilled multi-disciplinary input needs to be available to support staff to deal more effectively with people with dementia. This should include a Consultant Nurse/ Clinical Nurse Specialist available to give both case specific advice and to assist with staff learning and development in this area more generally. The Welsh Assembly Government should commission further work exploring the treatment of and experience of people with dementia in hospital, and ways to improve, building on the National Dementia Action Plan for Wales and the associated 1000 Lives Plus work programme. This should bring about better care for older people with dementia in hospitals in Wales.

3

Lack of timely response to continence needs was widely reported and is unacceptable

The Panel's findings highlighted that patients' toileting needs are not always met and that there is merit in the supportive role of the specialist continence advisor to support ward staff. The lack of a prompt response to calls for assistance, failure to prioritise toileting needs in care routines, and an over reliance on pads was found to result in avoidable incontinence. This is unacceptable and should stop immediately. It has a humiliating and degrading effect on older people, is a major source of distress and an assault on their self respect. It is contrary to the spirit of the United Nations (UN) Principles for Older Persons.

Detail of Recommendation 3

Health Boards and the Trust should prioritise the promotion of continence and management of incontinence. They should ensure that staff at all levels are empowered, trained and aware of the impact of both the ageing process and acute health conditions on continence. They should also devise an appropriate method for identifying older people's experience of continence care.

4

The sharing of patients' personal information in the hearing of others should cease wherever possible

When an older person is in hospital, the traditional ward round almost inevitably ensures that intimate personal information about their clinical condition and treatment will be heard by other patients and their visitors. This has become almost a given, something which just happens because of the environment in which someone finds themselves.

There needs to be much more focus on the rights of patients, as provided for by the Human Rights Act. It is time to challenge existing practice and to raise people's expectations of dignity and privacy during their hospital experience.

Detail of Recommendation 4

Clinical staff should regard their routine review of patients as a series of individual consultations, and whenever possible these should take place in a ward facility which is accessible, appropriate, and offers privacy.

5

Too many older people are still not being discharged in an effective and timely manner and this needs urgent attention

It is vital that the current public finance situation is not allowed to have a negative impact on discharge planning and partnership working, including within and between statutory and third sector organisations.

It is a false economy to leave people in hospital and we have to find smarter ways of working in the current budgetary context.

The process of discharging an older person from hospital in an effective and timely way remains problematic and unsatisfactory. This is despite much activity and numerous reports on the issues in Wales.

Recommendations

The impact on older people caught up in this process can be disheartening and even debilitating as they can lose significant function, making it much harder to regain an independent life. The system can actually serve to institutionalise older people.

The Panel heard considerable evidence that the process of assessment and discharge is not working effectively. This included accounts of delays in care packages, particularly for those with more complex needs or dementia; cases of inadequate engagement with social services especially for people in hospitals outside their home county; and variation in the level, quality and timeliness of communication about discharge plans.

Discharge planning should be an integral part of the admission procedure so that steps can be taken from the outset to ensure that older people do not languish in hospital when they are clearly well enough to leave. Learning from good practice including effective discharge schemes run by the third sector is important.

Effective discharge planning needs to be driven forward with urgency at a national level by the Welsh Assembly Government and at a local level by Health Boards, the Trust and Local Authorities.

Detail of Recommendation 5

Health Boards, the Trust and Local Authorities should jointly develop more focused and effective commissioning of services and care for older people, including those with dementia, in order to reduce further the level of delayed discharges; and support this work through more robust embedding of Social Services staff in this process through ward level multi-disciplinary teams.

Resourcing the care of older people in Wales

6

The appropriate use of volunteers in hospitals needs further development, learning from successful initiatives

The Panel saw encouraging and inspiring examples of volunteers contributing positively to older people's hospital experience. Health Boards and the Trust should recognise the expertise of the third sector and work with them to realise the potential of appropriate, imaginative use of volunteers. With professional management, good induction and support at ward level, using volunteers can have tangible benefits. It is an area where relatively modest amounts of expenditure can realise benefits of a value far in excess of the funds invested.

Detail of Recommendation 6

Health Boards and the Trust should ensure that their hospitals further develop imaginative volunteer programmes to enhance patient experience, building on existing successful initiatives.

7

Staffing levels have to reflect the needs of older people both now and in the future

In a context of financial constraints, but also of an increasing older population, effective planning of staffing levels is crucial to the success of the health service in Wales. The key issue for public services now is learning to do more with less.

The Panel observed variation in staffing levels and were concerned that ward managers were sometimes unaware of the necessary staffing complements to run their ward appropriately.

Amongst many older people and their relatives, there was a perception that staff levels were too low, adversely affecting staff responsiveness and the time available for meaningful interaction with older people.

Recommendations

It is important to acknowledge that it is not just about staff numbers. Even on some very busy wards, the Panel saw how a positive ward culture can result in better outcomes despite limited staff resources. There are established tools for assessing staffing numbers and there must be greater transparency, both throughout the NHS in Wales and amongst the general public, of the appropriate levels of staff needed in our hospitals.

Detail of Recommendation 7

The Welsh Assembly Government, building on existing tools as a guide for determining staffing levels, should develop and implement a tool for Wales to determine both appropriate staffing levels and how staff should be deployed. This work should encompass current and forecast levels of need in relation to the care of older people.

8 Simple and responsive changes to the ward environment can make a big difference

When opportunities arise to undertake the refurbishment, redesign or construction of hospital facilities, they must reflect the preferences and needs of the people who will use or work in them.

This includes the provision of adequate and appropriately located toilet facilities, and a mix of bays and single rooms that reflects expressed preferences of older people.

Change need not involve major construction schemes, but wherever possible opportunities need to be taken to make simple changes such as clearer signage and use of colour, to improve existing wards for the benefit of all, especially patients with dementia.

Detail of Recommendation 8

The Health Boards and the Trust should, in collaboration with older people and their families and carers, make changes to ward layout which are most beneficial. This is to ensure all patients have satisfactory access to ward facilities.

The Health Boards and the Trust should work together to devise and adopt an inclusive consultation process with patients, their families and carers and a representative mix of staff of all grades and across all roles that takes account of the principles of good design when refurbishing or building hospital facilities. The needs of those with sensory loss or dementia should be central to this process.

Creating the conditions for greater dignity and respect in hospital care

9

Effective communication can raise patient expectation and involvement and can improve their hospital experience

Older people and their relatives and carers demonstrated in their evidence to the Panel that they understand and empathise with workloads of hospital staff. Yet they did not show a similar level of understanding or demanding of their rights, nor did they have high expectations of how they should be treated.

Hospitals need to make clear to older people, their families and carers, what they should expect in relation to the quality of their care, including how staff will respect their dignity and rights. The way in which staff communicate and involve people in decisions should, from admission onwards, positively reinforce a person's expectations of quality care.

Support needs to be made available, including the provision of equipment to aid those with sensory impairment, and through the provision of advocacy for those who need it, so their voices can be heard and their experiences captured.

Recommendations

Detail of Recommendation 9

The Health Boards and the Trust should provide older people, their families and carers, with a clear explanation of their right to receive good quality, dignified care. This must take careful account of sensory loss or other barriers to effective communication. Staff should maintain standards of communication and involvement which reinforce dignified care.

10 **The experience of older patients, their families and carers should be captured more effectively and used to drive improvements in care**

The need to be more responsive to the individual requirements of older people in hospital is a cross-cutting theme in our report. We have found significant cause for concern in, for example, the areas of continence care, assistance with eating and drinking, communication and arrangements for discharge. We have also found that there is considerable variation in the quality of care across Wales and even within the same hospital. We did find examples of very good practice. However, in other areas, standards of care must be raised to meet that of the very best wards and hospitals.

Knowledge of the experience of older people in hospital and whether they are treated with dignity and respect is essential in order to help drive change, to identify good and poor practice, to determine progress, and to assist learning and improvement across the NHS. We found that the current arrangements for capturing the experiences of patients were not sufficient to allow their voices to be heard; they do not collect adequate numbers for robust analysis, or allow for comparison between organisations. This has implications for considering experiences of patients in general, but as noted elsewhere, the majority of patients are older people.

There should not be a reliance on complaints as the main means of understanding the patient experience. Many people are either reluctant to complain, cannot complain because of their illness, or do not have relatives or carers to advocate on their behalf. We recognise that there are efforts being made in some places to collect patient experience data, but more needs to be done.

Detail of Recommendation 10

The Welsh Assembly Government should lead on, develop and implement a clear, consistent mechanism through which Health Boards and the Trust will capture and act on the experiences of older patients, including those unable to speak for themselves.

This mechanism would allow qualitative data about older people's experience to be captured, understood and used to drive organisational learning and positive change. Results should be made publicly available in a form allowing ease of understanding and comparisons over time, on a Wales-wide and on a Health Board and Trust basis.

Health Boards and the Trust must demonstrate, for example, through Board meeting records, how they have taken account of and acted on, their patient experience results. Board members should also play a direct role in assessing the patient experience through means that include regular ward visits to both speak to patients and their families and observe care delivery.

11

Good practice should be better identified, evaluated and learnt from to bring about improvements in care

Health Boards, the Trust and staff at ward level need to take responsibility for identifying, sharing, assessing good practice and building their services based on what is shown to work. The Welsh Assembly Government has an important role in ensuring the effective dissemination and uptake of good practice.

We recognise that progress has been made through a number of existing mechanisms including the National Leadership Innovation Agency for Healthcare, Good Practice Wales web portal, and the Social Services Improvement Agency.

Recommendations

Detail of Recommendation 11

The Welsh Assembly Government should drive forward the evaluation and adoption of good practice across Wales, with an emphasis on securing positive, demonstrable changes in practice in the care of older people. The Welsh Assembly Government should hold the Health Boards and the Trust to account for their success in adopting good practice which enhances dignified care, or justifying why they have not done so.

12 All those working with older people in hospitals in Wales should have appropriate levels of knowledge and skill

The Panel expressed concern that the ageing process and the implications for older people and their care, are not well enough understood by all staff. Skills development in caring for older people, including communication skills, was not as evident as it needs to be if current or projected needs are to be met.

Detail of Recommendation 12

The Welsh Assembly Government, Health Boards and the Trust should ensure that all staff caring for older patients acquire appropriate levels of knowledge and skill through continuing education and training.

The Welsh Assembly Government should ensure opportunities for those with high levels of training to specialise through a career framework appropriate for current and future need.

Review timeline

Hospital Review Timeline

■ April 2008 - January 2010

The Commissioner speaks to older people throughout Wales and gathers their views and priorities.

■ February 2010

Consultation on whether the focus for the Commissioner's first Review should be social care or health.

■ March 2010

The Commissioner announces that the Review would focus on dignity and respect in a health setting.

■ April 2010

The Panel of Inquiry is appointed.

■ May - June 2010

The Panel of Inquiry established the scope of the Review and the methods they would use to gather evidence.

■ June - August 2010

Public call for evidence about older people's hospital experiences.

■ September - November 2010

The Panel conduct visits at sixteen hospitals throughout Wales.

■ December 2010 - January 2011

The Panel analyse the evidence and prepare the report of their findings.

■ February - March 2011

The Commissioner considers the Panel's findings, and develops the recommendations.

■ March 14, 2011

Publication of the Review report and recommendations.

■ June 14, 2011

Deadline for responses to recommendations. The public bodies to whom recommendations are directed have three months to respond and demonstrate to the Commissioner what further action they will take to comply with the recommendations.

■ June - October 2011

The Commissioner will keep a register containing details of the recommendations and further action taken. The Commissioner can take further action to follow up the responses to the recommendations.

The way forward

Everyone who has given their time generously to assist with this Review rightly anticipates that the recommendations will lead to positive change. The publication of the Review report and its recommendations, signals the intention of the Commissioner to ensure improvements happen for the benefit of older people.

Implementation of the recommendations

Using the Commissioner's legal powers⁶ the organisations subject to recommendations in the report have been asked to provide, in writing by 14 June 2011, an account of:

- How they have complied, or propose to comply, with the recommendations; or
- Why they have not complied with the recommendations; or
- Why they do not intend to comply with a recommendation/s.

Formal written notices will be issued to any organisations which fail to respond or which provide inadequate information. If after this process the response received is not deemed satisfactory, the Commissioner reserves the right to draw it to the attention of the general public.

Recommendations register

The Commissioner is obliged to keep a register of the recommendations made in the report and the actions taken in response. The register must be available for the general public to view. It will be published on the Commission's website, and made available to individuals on request.

Working in partnership

Wherever possible the Commissioner will work with other organisations to monitor the implementation of her recommendations. Much of what has been learnt through this Review during the course of the last 12 months will apply equally to other care settings, and the Commissioner will work to spread this knowledge more widely.

NOTE: 6. Commissioner for Older People in Wales Regulations 2007, Reg. 15 (2007/398)

If you wish to receive a copy of the extended report or would like a copy of this document in an accessible format, please contact us:

Older People's Commissioner for Wales, Cambrian Buildings,
Mount Stuart Square, Cardiff CF10 5FL. Phone: 08442 640 670
Email: ask@olderpeoplewales.com www.olderpeoplewales.com