



*Alone we can do so little; together we achieve so much!*

## **NEWS UPDATE: JANUARY 2009**

Happy New Year and welcome to the January news update.

### **THANK YOU**

We are pleased to announce that we have now taken delivery of our bilingual leaflet. We would like to thank an individual, who wishes to remain anonymous, for designing the leaflet and negotiating with the *Howard Hunt Group, in Dartford, Kent* to produce 1,000 copies at no cost. We are very grateful for their generous support.

### **Forthcoming events**

#### *Dignity is More Than Just a Word*

#### *Perceptive professionals embedding dignity and respect in a care environment*

Monday 11 May 2009, Cardiff

The workshop is focused on fine tuning communication and listening skills to enrich relationships between patients/clients, relatives and carers and colleagues. [Email](#) for further information

We welcome your comments and suggestions. If you have any information that you would like to share with others please let us know and we will be happy to circulate it in the next newsletter.

If you are reading a copy of this email forwarded to you by a colleague we may not have your contact details. If you would like to guarantee a regular monthly copy of the mailing send your details to [info@dignifiedrevolution.org.uk](mailto:info@dignifiedrevolution.org.uk)

*A Dignified Revolution, Britannia House, High Street, Cowbridge, CF71 7AD*

### **GOOD NEWS CORNER**

In recent months we have found that a number of people (members of the public and professionals), who have experienced, or are concerned about hospital care, have taken the initiative to do something about it. Below, are some of the activities that we have come across.

### **General public activity**

#### *Butterfly scheme*

The Butterfly Scheme has its origins in Leeds, where one carer observed serious faults in the system of dementia care in the acute hospitals and decided to initiate change. Staff failed to realise her mother had dementia, so took history from her and gave or withheld drugs accordingly, despite the fact that the history was inaccurate. Instructions on physiotherapy were given to her and immediately forgotten, whilst lack of reorientation when staff approached led to unnecessary distress. Even when made aware of her dementia, staff often had no training in dementia care and no strategy for meeting her needs. From her experience of her mother's hospital care it was evident that there needed to be:

- an at-a-glance identification system available for hospital patients who have dementia-related memory impairment and wish staff to be aware of it.
- there must be an education drive to back this up with guidance for staff

The Butterfly Scheme is designed to allow people with a permanent dementia diagnosis to make this clear to hospital staff and will provide staff with a simple, practical strategy for meeting their needs. The patients will receive more effective and appropriate care, reducing their stress levels and increasing their safety and well-being. Butterfly status will be flagged up on computers in A & E. This is an opt-in scheme which it is hoped will, in time, be routinely offered nationwide via memory clinics at initial diagnosis. To find out more, please email: [barbara.hodkinson@ntlworld.com](mailto:barbara.hodkinson@ntlworld.com)

### *Professional Concern*

As mentioned last month, we have been contacted by a group called Professional Concern, which is based in Derby. The interests of their members are similar to A Dignified Revolution. They are a group of retired nurses who wanted to make a difference, so they approached the Director of Nursing at the local trust. They were welcomed warmly and invited to join audit teams and discussion groups. They have also been given a place at several discussion groups run by the Royal College of Nursing. Their focus is on enhancing basic nursing care. We have arranged to meet with members of the group on 30 March 2009

### *Enthusiastic individual*

We recently met a nurse from Northampton called Wendy Patel. She is interested in promoting dignified care in her local area, and through her contacts in other parts of England. She has already been very supportive by forwarding on details of A Dignified Revolution through her networks. Since meeting with us she has put together something for the local paper to gain interest in the immediate area and also for the bulletin which goes around the whole of the area where she lives. She has also made contact with the local WI. She is joining us in March to meet with Professional Concern. If you live local to Northampton and would like to make contact with Wendy, email [WPatel@aol.com](mailto:WPatel@aol.com)

### *Amanda Waring – 'What do you See?'*

Amanda Waring, an actress and producer, is very proactive in promoting dignified care. We attended the Gala Celebrity Evening that was held at BAFTA, London on 12 January 2009 which was an excellent opportunity to see how busy Amanda is. She has produced a DVD entitled [What Do You See?](#) which aims to raise awareness of how society treats older people. Amanda has also recently launched a new DVD and training pack which is focused around the transition to a nursing home and later in the year she will be launching another DVD and training pack focused towards end of life care.

If you are involved in helping to improve health and social services please get in touch and let us know what you are doing

### General statutory sector activity

#### *Transforming care at the bedside*

On Thursday a member of A Dignified Revolution attended a workshop at Hywel Dda NHS Trust which was focused around [transforming care at the bedside](#) (TCAB). It was an interesting and informative day which provided an excellent insight into an initiative that has the potential to:

- improve the patient's experience of care
- empower nurses
- help NHS organisations meet quality indicators

For more information email about TCAB [Annette.Bartley@cd-tr.wales.nhs.uk](mailto:Annette.Bartley@cd-tr.wales.nhs.uk)

#### *Share news of your work with Social Services Improvement Agency(SSIA) Cymru*

The [SSIA](#) was set up to support local authorities increase the pace of improvement and promote excellence within social services. There are plans to include a notable practice database on the site later this year and SSIA are currently looking for examples. They want to hear from anyone who has a scheme, project or way of working that has been particularly successful so that it can be shared with the rest of Wales. Visit the [website](#) to download and complete a proforma, or email [ssiaenquiries@wlg.gov.uk](mailto:ssiaenquiries@wlg.gov.uk) with your information

### ACTIVITIES

In January we:

- attended the Welsh Assembly Government Dignity in Care social care sub group meeting
- attended the Welsh Assembly Government National Coordinating group meeting
- made a presentation to the NIFTY Club to talk about A Dignified Revolution. The Nifty Club, based in Neath, has around 60 members and is a lively group with a full programme of activities running throughout the year
- ran a session on dignity for staff working in Southern Cross Nursing Homes in SE Wales. Around 40 staff attended the event and we have been asked to run another session. Southern Cross Nursing Homes now have designated dignity champions and every home has been provided with What Do You See? DVD

We will be:

- speaking at the re-launch to Pathways to Adapted Housing in Pontypridd on 28 January 2009
- meeting Professional Concern on 30 March 2009.
- participating in a workshop that is being held in Cardiff on 27 February 2009 to discuss the challenges that patients, relatives and carers experience during Continuing Health Care assessments and the decision-making that takes place
- attending a meeting of SHOUT, the voice of older people in Maesteg, on 5 May 2009
- speaking at the annual council meeting of Gwent Federation of Women's Institute on 22 April 2009

We have been contacted by the project officer for [Connect in Care](#). She has kindly offered to link our website to theirs as she feels that it would benefit those who access their website. Connect in Care is aimed at working with staff who care for older people wherever that care takes place i.e. in the community, the NHS & Care Homes in Scotland, to support learning and practice development in order to improve the quality and experience of care for older people

On behalf of the Nursing & Midwifery Council (NMC) we have circulated a draft of a public information leaflet that explains the [NMC guidance for older people](#) due to be published in the spring. The NMC are keen to receive comments to help ensure that it is appropriate for the audience to which it is intended

## FEEDBACK

"Congratulations on all this. I hope that 2009 will bring further success to the campaign. What you are doing is really important"

"Many thanks for the fantastically helpful news update. It is great"

"Thanks for sending the current news update and please continue to do so"

"Thank you. I will keep in touch, please keep up the good work"

## NEWS

### *What the dreadful treatment of this war hero tells us about compassion in the NHS today*

Aged 101, John Platt was sent away in a taxi to die by Salisbury District Hospital, wearing only a nappy and a set of ill-fitting pyjamas. He was discharged unable to feed himself and clutching a bag of soiled clothing. Read the full article [here](#)

### *An Alzheimer's patient lies in a grubby hospital bathroom because of a shortage of beds. Will the elderly ever be treated with dignity in Britain?*

In what her family describe as 'an [affront to human dignity](#)', Gladys Joynes, 79, was shunted into the bathroom for several hours. The grandmother was left next to an overflowing bin, a commode and a foul smelling walk-in bath. And with no power point in which to plug in her saline drip equipment, she swiftly became dehydrated and unresponsive

### *Fiona Phillips condemns government over Alzheimer failure*

The television presenter [Fiona Phillips](#) has condemned the Government's failure to keep promises to improve the care of Alzheimer's sufferers, and accused it of seeking to cut costs at the expense of thousands of overburdened carers. Miss Phillips said that tens of thousands of relatives are left to care for sufferers with little or no help from outside agencies, compromising their own health in the process

### *Starved to death in an NHS hospital: Damning inquiry highlights case of patient left without food for 26 days*

A vulnerable patient [starved to death](#) in an NHS hospital after 26 days without proper nourishment. Martin Ryan, 43, had suffered a stroke which left him unable to swallow.

But a 'total breakdown in communication' meant he was never fitted with a feeding tube. It was one of a number of horrific cases where the NHS fatally failed patients with learning difficulties; a health watchdog is expected to rule later this month

### *Angels of mercy*

In a [letter](#) featured in the Daily Mail on Friday 16 January 2009 Peter Laver from Thatchum, Berks described his treatment of a broken arm. "What I experienced was a service divided into specialist groups, each doing their jobs, resulting in the patient getting the medical treatment they needed but none of the emotional support. The patients were reduced to disregarded spectators. The angels of mercy have vanished. There are no more kindly but efficient nurses to say a soothing word and straighten some bedclothes there. For me, it was endurable because I was out in four days. For some patients, this is the place they have come to die. God help them that they should end their days in such a disheartening place"

### *Have your say in planning an older people's food charter*

Visit the [Welsh Food Alliance website](#) to complete the online survey

### *Can you help stop abuse?*

The Department of Health is currently consulting on 'No Secrets' the guidance on keeping adults safe (for England). This document aims to stop all forms of abuse of older people. If you can help the Alzheimer's Society by speaking to the media about any experiences you may have of abuse please call the press team on 020 7423 3595 or email [press@alzheimers.org.uk](mailto:press@alzheimers.org.uk)

### *Do you care what the public thinks of the care industry?*

Has the recent media focus on negative care stories affected how you feel about working in the health and social care industry? If so, why not take 30 seconds to answer four short yes or no questions to help them find out how you feel and more importantly, to get the public behind the industry. They want to get the voice of the industry heard and make sure that the media know about all the great work staff in the care industry is doing. To share your views [click here](#)

## **RESOURCES**

### *Care homes pioneer abuse helpline*

The care provider Southern Cross is offering an abuse helpline to residents in all of its 735 care homes in the UK. It is the first scheme of its kind, and the company is the only major care provider offering such a service. The [helpline](#) is staffed by trained advisors from the charity Action on Elder Abuse. They will not need the permission of Southern Cross to alert authorities to any problems, as they are entirely independent. Action on Elder Abuse hopes other major providers of care homes might follow this lead.

### *Facing up to the cost of care*

With the announcement that the UK's fastest growing age group is now those aged 85 years and over, comes some startling facts of current care home costs. It is reported that the average cost of a single room is now £24,700 per year, with that escalating to £35,000 annually in a nursing home situation. Care Directions has teamed up with NHFA to provide comprehensive guidance on this topic. An [enquiry form](#) is available on the Care Directions website which can be used to gain further information

### *Measuring dignity in care for older people*

This study was carried out to identify indicators of dignity in care for older people. The aim was to make recommendations on the best way to measure each of the Help the Aged domains of dignified care: personal hygiene, eating and nutrition, privacy, communication, pain, autonomy, personal care, end-of-life care and social inclusion. As a result of the [research](#) a set of proposed indicators have been developed

### *Good communication enhances the patient experience*

In a Department of Health survey, culminating in the report [Now I feel tall](#) good patient experience was seen as synonymous with 'having information to make choices, to feel confident and to feel in control'

### *National guidelines for assessing pain in older people*

National [guidelines](#) have been developed for assessing for pain in older adults

### *Religion or belief: a practical guide for the NHS*

This [guidance](#) is designed to assist NHS organisations to implement and comply with the requirements of legislation on religion or belief enacted recently, and also provides general practical guidance around the issues relevant for the NHS

### *Commissioning End of Life Care*

This [report](#) was produced by the NHS National End of Life Care Programme team in conjunction with the Department of Health. The information aims to support the commissioning of a whole-systems approach to end of life care and is intended for PCTs, practice based commissioners, mental health service commissioners, older people service commissioners and long term condition service commissioners

### *What are the Mental Capacity Act deprivation of liberty safeguards?*

This [leaflet](#) provides a brief general introduction to the Mental Capacity Act Deprivation of Liberty Safeguards and has been specifically designed for care homes and hospitals to help staff understand what the safeguards will mean for them and their service users

### *Expert dementia support service for Scottish voluntary sector*

The Dementia Services Development Centre, University of Stirling, has established a new support service for frontline people working in dementia care in voluntary organisations and community groups across Scotland. The [liaison service](#) gives access to a range of expert information and training that is often not affordable to voluntary organisations. To find out more about the service and opportunities, contact Jemma Galbraith on 01786 467740, e-mail: [jemma.galbraith@stir.ac.uk](mailto:jemma.galbraith@stir.ac.uk)

## **PUBLICATIONS**

### *Take my hand: The extraordinary story of a girl named Janis*

A [powerful account](#) of a young woman's death from undiagnosed encephalopathy

## **EVENTS**

### *Ageing Population 09*

Thursday, 29 January, 2009

QEii Conference Centre, London

Ministers are warning that the UK's social care system is heading towards a £6bn funding gap unless there is radical reform. This groundbreaking [conference](#) will debate the government's strategies on the future funding of social care, and will also discuss how best to utilise the wealth of knowledge and skills that the ageing population can bring to the 21st century workplace

*Dementia, dignity and the challenge of an ageing society*

Thursday, 26 February 2009, London

Supporting people with dementia and their carers in health and social care.

This event is for health and social care staff who work with people with dementia and their carers, and those who work with older people. It also includes recommendations relevant to commissioners, managers and coordinators of health and social care.

For more information phone 020 7347 3574 or email [ebookings@lexisnexis.co.uk](mailto:ebookings@lexisnexis.co.uk)

*Action on Elder Abuse National Conference 2009*

Monday, 23-24 March 2009

East Midlands Conference Centre, University Park, Nottingham

For more information email [daisygoodstien@elderabuse.org.uk](mailto:daisygoodstien@elderabuse.org.uk)

*RCN Nursing Older People conference*

Wednesday, 1 April 2009

For more information email [pat.anslow@rcn.org.uk](mailto:pat.anslow@rcn.org.uk)

*World Elder Abuse Awareness Day - 15 June 2009*

World Elder Abuse Day is now approaching its 4th year and Action on Elder Abuse want to make it an important date in everyone's diary. For more information email

[worldelderabuseday@elderabuse.org.uk](mailto:worldelderabuseday@elderabuse.org.uk) or call 0208 765 7000. Action on Elder Abuse has launched a series of exciting challenge events, including skydiving, trekking and running. If you've ever wanted to trek the Inca Trail, freefall from 10,000 feet or sledge across Lapland with huskies (to name but a few), visit <http://www.elderabuse.org.uk/> for more information

## **THE FUNDING OF A DIGNIFIED REVOLUTION**

The common experience of how close relatives, whilst in hospital, had not been treated with respect and, as a result, lost their dignity led a group of individuals to establish A Dignified Revolution in January 2008.

A Dignified Revolution aims to ensure that older people are cared for with dignity and respect in hospital. We do this by raising awareness of dignity and respect issues to health professionals and to the general public

If you would like to help, we would like your time most of all. However, some cash would also be useful. £15 covers the cost of a person attending an awareness day; £30 covers the cost of printing and posting 100 leaflets; £100 covers the cost of one trip between North and South Wales to raise awareness of A Dignified Revolution.

Donations will help us to continue our work – so please give generously if you think our cause is worthwhile. Not a penny will be spent on administration or overheads – we don't have any!

Cheques should be made payable to A Dignified Revolution.

We want to remain focussed on our goal of helping older people retain their dignity whilst in hospital. In order to avoid being diverted onto other issues and priorities, we do not seek statutory sector funding (although unsolicited grants will be accepted). So your support is important and will help to make a difference.

## **ACKNOWLEDGEMENTS**

We would like to thank the following people for giving their time and expertise to help develop resources to support A Dignified Revolution:

**Lance Webster** – for the design of our logo

**John Dixon** – for the development of the website

**An individual** (who would like to remain anonymous) for her production of our leaflet

**The Welsh Language Board** – for the translation of our leaflet

**An individual** (who wishes to remain anonymous) for her production of the bilingual leaflet

**Howard Hunt Group**, Dartford, Kent for printing 1,000 copies of our bilingual leaflet

## **CONTACT DETAILS**

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