Hello Everyone,

Here is the autumn issue of the Dignity in Care e-newsletter. I am sorry that I didn’t manage to produce the spring issue of the Dignity in Care e-newsletter and so I have included links to the presentations given at the National Dignity Council Conference which was held earlier this year on 1st February 2016, Dignity Action Day.

For those of you who were not able to go, it was a brilliant day – very inspiring and highly motivating.

I would like to thank everyone who has allowed me to use their stories or news items in this issue and hope that you find the information contained in this newsletter insightful and helpful.

Sally Latham

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Dates for your diary…

- 14th November 2016 – Talking Care – Kassam Stadium
- 16th November 2016 – Age UK Oxfordshire AGM and Dignity in Care Awards
- 1st February 2017 Dignity Action Day – what are you intending to do?
- National Memory Day – 18th May 2017

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The next …

**Oxfordshire Dignity and Dementia Champions’ Network Meeting**

**Friday 16 December 2016**

**10.30 am to 12 noon**

Oxfordshire County Council  
Meeting Room 2  
County Hall, New Road, Oxford OX1 1ND

Our guest speaker is Eddy McDowall  
Oxfordshire Association of Care Providers (OACP)

Eddy will be giving a short briefing on the Oxfordshire Association of Care Providers and facilitating discussions on social care in Oxfordshire
National Carers Rights Day
‘Caring Matters’ Conference 2016

If Caring Matters to you this conference is an important event for both carers and professionals.

Guest speakers include;

Dame Philippa Russell DBE, Emeritus Chair, Standing Commission on Carers.
Sarah Taylor, High Sheriff of Oxfordshire
Caroline Heason, Head of Patient Experience, Oxfordshire OUHT

Expert Seminars including;
Welfare Benefits Advice, Mindfulness, Assistive Technology, Rally Round for Carers, Singing for Health and others to be confirmed.

Over 20 information stands will provide advice, connections and support throughout the day.

Date: 25th November 2016
Time: 9.30am - 4.30pm
Venue: Kassam Stadium, Oxford

To book please visit:
www.carersoxfordshire.org.uk/cms/news
Or call 01235 520463
Sign up to the following newsletters via these websites

✓ National Dignity in Care e-newsletter
http://www.dignityincare.org.uk/Dignity_in_Care_news/Newsletters/

✓ Carers Oxfordshire e-newsletter
http://www.carersoxfordshire.org.uk/cms/content/sign-our-newsletter

✓ Age UK Oxfordshire e-newsletter
http://www.ageuk.org.uk/oxfordshire/news--campaigns/newsletter-sign-up/

✓ Unforgettable e-newsletter
https://www.unforgettable.org/newsletter/?SID=c4uio5immtu145b71ni7c3blc4

Some great videos for use in training

• The Care Act 2014 (animated cartoon)

• Living with dementia
http://www.scie.org.uk/socialcaretv/video-player.asp?v=living-with-dementia&dm_i=4O5,2TGTY,5HYUSI,A8JO7,1

• What Do You See?
http://www.amandawaring.com(films/what-do-you-see

• Dignity - Little Things Make a Big Difference
http://www.youtube.com/watch?v=ueLqAJRxKpQ
A DAY IN THE LIFE OF AN INFORMAL CARER
(written by Christine Tucker when she was a carer for her husband)

It's 6.30 am and the alarm clock reminds me that in half an hour two trained carers will be on the doorstep. The intercom (between my bedroom and my husband's annexe) has been mercifully silent all night. This is not always so. Trips downstairs during the night are sometimes necessary, either to answer a call or to check that all is OK.

Put the kettle on – welcome the new day with my husband and listen to the catalogue of aches and pains which have happened during the night! Also an urgent plea for the loo. Mostly incontinent, but such demands cannot be ignored. Moving husband from bed to commode necessitates the use of a hoist – strictly speaking a double handed job but can just about be achieved by one person. False alarm this time, so back to bed. A cup of tea needs to be supervised as frequently finishes up in the bed having successfully wetted vest, pyjamas and bedding!

Carers arrive at 7 am and tackle the almost impossible task of washing, shaving, dressing and transferring husband to his chair in half an hour. They are remarkably cheerful considering they have no drive time and already late for their next call. Why? They do such a vital job in such conditions with so little recognition and remuneration – angels come to mind!

Whilst the carers are in charge, I shower, dress, read emails, and prepare breakfast. I feed my husband his breakfast – a slow job and eat my cereal at the same time. Give medication and more drink. Failure to do this can result in dehydration and resultant mental confusion adding to the already confused state due to vascular dementia. Heart sinks, the carers have left and there is another request for the loo! Another trip by hoist to the commode. Then the washing and attention to pressure areas. Remember the nappy changing? Not much different except the baby is 12 stone!

By this time it is getting on for 10 am – time to tackle washing – lots of it and housework, shopping and cooking – all tasks punctuated by requests for drinks, painkillers, moves of position or just conversation started but not completed because memory has failed! Checks on medication must be made as pills run out so easily and 48 hours are needed to get more.

Shopping trips lasting more than an hour need a request to an independent carer (trained). This is also true of trips for me to dentist, hospital etc.

Coffee breaks need supervision for the same reasons as early morning tea!

Hair washing, manicures, pedicures when necessary must be attended to relieve pressure areas. During the morning there has been little or no coherent conversation but occasional smiles indicate all is well.

Lunch can take an age – lack of co-ordination makes it a messy business but it is important to try. Lots of patience needed! Another change of pad after lunch so hoist in use again. Housework and garden are suffering from lack of attention but both on the back burner until who knows when! Choir practice, Italian lessons and other hobbies are also casualties.

Continued on next page…
The need for good nutrition for the healing of leg ulcers demands thought for supper. No ready prepared pizza and chips for us! And again drink and fruit - bowels can be another hazard if not attended to. Macrogel can have explosive results. Please not on my shift plead the carers!! Soon after supper, the carers arrive to put my husband to bed – a reversal of morning routine. What a relief to share responsibility for half an hour. After evening drink I am relatively free apart of course from demands for drink, pillow adjustments, and pain relief. I sit down on husband’s Rise and Recline chair – such bliss, and promptly fall asleep!!

This is just one day – a reasonably calm day – some days however can be hell! Especially if it necessitates dealing with officialdom. Do not officials whose job it is to deal with the needs of the elderly and infirm, know that carers cannot spend hours on the phone waiting to be transferred from one office to another, try organising hospital transport or dental appointments!! Stress levels can get dangerously high!

Am I a bit disgruntled? You bet I am! I’d have to be a saint not to be. And I’m no saint! I have been a carer for 12 years and have seen my friends go on theatre trips, outings and holidays whilst all our hard worked for savings are disappearing rapidly to pay for ever increasing care bills. Caring for someone at home is very, very hard work. Nobody to bring me a cup of tea in bed. If I don’t feel well, I have to struggle on. No sick leave for me, no deputies to take over and no holidays! And the constant worry of what if I run out of money.

It would be churlish for me not to mention some good local initiatives. I am grateful for the GP respite money which I have received. But of course it is a drop in the ocean when you count the real cost of caring. What is needed is a fundamental change at government level. The situation can only get worse unless tackled now.

What a joy it would be to have a well-funded, fully co-ordinated service with primary care, NHS, social services and the independent caring companies all working and communicating with each other.

Dignity in Care Awards 2015

Mrs. Christine Tucker on the right, receiving ‘Josie’s Award’ from Diana Roberts, Chair of Age UK Oxfordshire and Action for Carers Oxfordshire

(Click on the link below for full details of last year’s winners)


The winners of the 2016 Dignity in Care Awards will be announced at the Age UK Oxfordshire AGM on 16th November 2016
What is a carer?

A carer is someone who provides unpaid care and support to a family member or friend who has a disability, illness, mental health problem or who needs extra help as they grow older.

For some, taking on a caring role can be sudden: someone in your family has an accident or your child is born with a disability. For others, caring creeps up unnoticed: your parents can’t manage on their own any longer or your partner’s health gradually worsens.

The amount and type of support that carers provide varies considerably. It can range from a few hours a week, such as picking up prescriptions and preparing meals, to providing care day and night.

Caring will touch each and every one of us in our lifetime, whether we become a carer or need care ourselves. Whilst caring can be a rewarding experience, it can also have a damaging impact on a person’s health, finances and relationships.

Facts about carers

- 6.5 million people in the UK are carers; that’s 1 in 8 adults
- By 2037, it is estimated that the number of carers in the UK will rise to 9 million
- Every day another 6,000 people take on a caring responsibility – that equals over 2 million people every year
- 58% of carers are women and 42% are men
- Carers save the economy £132 billion per year, an average of £19,336 per carer
- Over 3 million people juggle care with work, however the significant demands of caring mean that 1 in 5 carers are forced to give up work.
Show your commitment to ‘Dignity’ Poster

This ‘Ask Me’ poster is one of a number of resources from the National Dignity Council which can be downloaded from http://www.dignityincare.org.uk/Resources/resource/?cid=8370 and displayed by organisations to show how settings are signed up to Dignity in Care.

Promoting Dignity with the National Dignity Council

Ask me how Dignity is promoted here

Dignity in the heart, mind and actions

Become a dignity champion at www.dignityincare.org.uk
An update from the National Dignity in Care Council

77803 registered Champions currently

The National Dignity Council Conference was held on 1st February 2016

Annual Conference Presentations

5. http://www.dignityincare.org.uk/_library/Dr_Rekha_Elaswarapu_NDC_Dignity_at_work_presentation.pptx

The National Dignity Council AGM – September 2016

The National Dignity Council held its AGM on 19th September. The meeting was attended by five champions in addition to the Trustees. The Minutes of the AGM have been posted on the website and there is a link in the September Dignity in Care newsletter.

Adam Probert was welcomed as a new trustee and Liz Taylor resigned as a trustee, but will stay on as the Hon Sec. Jan Burns MBE thanked all Champions for their hard work over the last twelve months.
The true cost of dementia…

Julia Stuart of the Alzheimer’s Society sheds lights on the true cost of dementia on the UK’s finances and resources and what it means for care received…

The Health Secretary’s ambitious aim to make the UK the most dementia-friendly society in the world by 2020 will fail without a dramatic increase in social care resources. In March Jeremy Hunt announced a series of commitments to boost diagnosis rates, raise awareness and encourage research.

But the Alzheimer’s Society estimates that the amount spent by government on social care for people with dementia will need to more than double, from £3.7bn in 2015, to £8.5bn by 2030 just to keep pace with demand and care inflation.

“The NHS could be the best at looking after people with dementia, but that will be irrelevant if something isn’t done about social care,” said Laurie Thraves, senior policy officer for the charity. “And doing something about social care is about the money, essentially. Unless the money is there, I don’t think we can ever be the best in the world.”

Around 70% of people in care homes have memory problems or a dementia diagnosis. Social care is also critical for those with dementia living at home, as many need help washing and dressing. “Some people with dementia who live alone won’t be able to perform these basic tasks, or they’ll do them badly,” said Thraves. “If someone is being cared for, these needs put additional pressure on the carer. Caring is a full-time job and people need as much help as they can get. It’s particularly tricky when you have 2 frail elderly people, one of whom has dementia, and you’re essentially asking the other frail person to do a lot of heavy lifting.”

Carer burnout is one of the most common reasons why someone with dementia is admitted to a care home or a nursing home.

When people with dementia are unable to get care in the community they often reach a crisis point more quickly and end up in hospital, where they spend a lot longer than other older people. Many become less mobile, their muscles waste, and they find the environment more distressing and confusing than their peers do. A significant proportion will then be admitted to a care home rather than return to their own home.

“The vast majority of NHS spend goes on the final years of our lives. We know that at the very end of life people with dementia are often admitted to hospital for expensive acute care when they could be cared for in a care home if they had access to specialist palliative services which people with other long-term conditions such as cancer are more likely to be able to access,” he said.
The “true cost of dementia” article continued…

There are currently 850,000 people with dementia in the UK. This is predicted to rise to 1 million within 10 years, and reach 2 million by 2050. A third of people with dementia are already living in care homes. Numbers are expected to increase from 313,000 to just under half a million by 2030. This would require the creation of an estimated additional 175,000 care home places for people with dementia alone.

Since 2010, £4.6bn has already been taken from the adult social care budget, resulting in an estimated 500,000 older and disabled people being denied access to care. The government has promised around £1.5bn through the Better Care Fund, which tries to integrate spend between health and social care, but the money won’t materialise until between 2019 and 2020.

The total cost of dementia to society in the UK already stands at £26.3bn, which is enough to pay the energy bill for the entire country. Of that £4.3bn is spent on healthcare costs and £10.3bn on social care, met partly by local councils and partly by people with dementia themselves. A further £11.6bn is contributed by the work of unpaid carers, many of whom have had to give up their jobs to look after someone with dementia, which can have a devastating effect on their own finances and career.

In 2 years the global cost of dementia is estimated to reach $1 trillion, according to the World Alzheimer Report 2015. The report, commissioned by Alzheimer’s Disease International, also found that the costs of dementia in Europe increased by 25% to $300bn last year.

“The best case scenario is that the government realises that failing to invest in the right support in people’s homes, care homes and residential homes is creating additional costs for the NHS, and it’s also destroying the lives of vulnerable older people,” said Thraves.

“We certainly welcome Jeremy Hunt’s commitment to making the NHS better for people with dementia, but that’s only half of the solution. We won’t be the best in the world until we have a social care system that is adequately resourced and on a sustainable financial footing.”

Julia Stuart
Alzheimer’s Society
www.alzheimers.org.uk