RESPONSE TO WELSH GOVERNMENT CONSULTATION
‘TOGETHER FOR A DEMENTIA-FRIENDLY WALES’

1 APRIL 2017

About tide – together in dementia every day

Tide is the UK wide involvement network for carers of people living with dementia, hosted by the Life Story Network CIC. We do not provide direct support to carers in their caring role as many other organisations do this. Rather, we enable carers to get involved to influence policy, practice and research. We offer a development programme to help them to recognise themselves as experts by experience and to give them the confidence and skills to be able to speak up and tell their stories with impact. More information about Tide is available here: www.tide.uk.net

We have a growing membership in Wales and took the opportunity afforded by the consultation on the draft strategy to gather views from members and other carers about what would make caring for those they look after easier, as well as how they might get involved locally and nationally within the principality to influence change. We also had feedback that some carers did not feel they had had the opportunity to speak up about their own needs during the consultation, but rather these had been aligned with the needs of those they were caring for.

Building on conversations with individual carers and a group in Anglesey, we organised three events for carers in North Wales in Anglesey, Gwynedd and Conwy, in partnership with Carers Outreach and Bangor University’s North Wales Dementia Network. Some carers who were unable to attend the events sent us their individual responses.

The carers we met had clear ideas about what would make it easier for them to look after the people they cared for. We refer to these at the appropriate point in the draft strategy and the full list is attached as Appendix One. We asked carers to choose the three that they regarded as the top priorities. Although all were identified as important by at least two people, the ones that came out as top were:

1. A single point of contact or a named person to go to for advice & information
2. Respite care that gives more choices than admission to residential care
3. A structured programme of post diagnostic support for you and the person you care for
4. Opportunities to meet with other carers (peer support)
5. Recognition of your role as a carer and your expert knowledge of the person you care for
Together for a dementia-friendly Wales
The view of some carers we talked to was that ‘dementia-friendly’ is too weak and some people with dementia and carers think it is paternalistic – the community graciously extending the hand of friendship. They believe that people with dementia and carers have equal rights as citizens to be included and play an active part. We also note the reference to dementia-supportive communities on page 18: this is confusing terminology. Given that the draft strategy states the aspiration to deliver support and services within a rights-based approach, we therefore recommend that the strategy should be entitled ‘Together for a dementia-inclusive Wales’.

The seven themes
Carers were unanimous that carers of people living with dementia should constitute an additional theme. They are the biggest workforce in dementia care, saving the Welsh economy £1.4 billion a year, and if they decided to down tools the NHS and social care would collapse.

As their needs are unique (because dementia affects everyone differently) these carers require increasingly specialised understanding and support outside of current provision from established statutory services and generic carer organisations. It is recognised that a diagnosis of dementia is given not only to the individual, but also to the carer and wider family. We believe that if carers of people with dementia are enabled in the right way, they are an asset that can be used positively to address the increasing needs of an ageing population, the growing numbers of people with dementia and the impact this has on carers who bear the brunt of caring. Carers themselves are campaigning for recognition as equal partners in care.

The majority of people with dementia are cared for at home by a relative or friend. The average age of (unpaid) family carers is between 60 and 65 years; many are much older and as the caring role is taken on the demands increase and the individual caring for a person with dementia will experience a loss of confidence and self-esteem. Often the carer will become the second patient needing care and support themselves.

This has an increasing economic impact on the state – for example health, social care and business – as well as significant impact on the lives of carers and those cared for. Equally when the caring journey ends it can be difficult for former carers to re orientate themselves back into the workplace and community as they experience social isolation and a loss of confidence, arising from disconnection from their friends, family and wider social networks.
For these reasons, we recommend that ‘Carers as equal partners’ should be added as a theme in the strategy, so that they have equal prominence, alongside the needs of people living with dementia.

Some carers wanted to add another theme – that of co-ordination of care. Although working together and joining up services are occasionally referenced in the draft strategy (on page 33, for example), carers suggested that they merit specific attention. The fragmentation of services and the disjointed way in which some professionals work have major impacts on the lives of people with dementia and those who care for them, causing immense frustration and wasted energy as carers themselves try to act as co-ordinators of care.

The challenge of dementia
It is disappointing that this section makes only passing reference to carers – the largest part of the workforce looking after people with dementia. The number of carers in Wales should be included.

The structure of the plan
Whilst we fully support a rights-based approach to meeting the needs of people with dementia and carers, we have some reservations about the ‘pathway’ approach. Pathways may be appropriate for cardiac rehabilitation or a hip replacement, but as the draft strategy points out, everyone experiences dementia differently – be they the person with the diagnosis or their carer – and the linear nature of a pathway unhelpfully suggests that everyone’s dementia will progress in the same way. People are diagnosed at different stages of the illness, there are over 100 different types of dementia and people’s needs and experiences will vary depending on their physical health, economic circumstances and support networks. Dementia rarely travels alone.

We prefer the concept of a ‘network’ rather than a pathway; this emphasises the need for collaborative and joined up working between different agencies and professionals.

Monitoring Delivery
We suggest that the strategy merits a specific Dementia Delivery Assurance group. The Older Persons Delivery group may miss the specific needs of people with younger onset dementia. Many carers we met had reservations about dementia being seen as a mental health issue; it is an organic disorder of the brain.

Risk reduction and delaying dementia onset
We challenge the content of the ‘notable practice example’. We do not believe that there are 40 communities who are either ‘dementia-friendly’ or working towards being so. No community will ever be dementia-friendly as it only takes one person to have a bad experience that undermines this claim. Communities and organisations can only ever be working towards achieving that status. The interchangeable use of ‘dementia-supportive’ and ‘dementia-friendly’ is confusing.

Further, the Dementia Friends programme is a great initiative – but it is very basic awareness raising and we have noted that some organisations claim to have ‘trained’ their staff in dementia, having held a Dementia Friends session which may only last 45 minutes. The strategy should make this clear and that there is a need for more specific training in dementia that takes people from awareness to understanding, so that they can better respond to the needs of people with dementia and their carers.

We therefore recommend that the action point on page 18 should read:
Increase the number of people in Wales who are able to recognise dementia and understand where to access additional support through the expansion of the Dementia Friends programme of awareness raising, more specific dementia training that gives people skills and competences and the development of dementia-inclusive communities.

Recognition and identification
This can be particularly challenging for carers who may notice changes in their loved ones who may be reluctant, or refuse, to seek help themselves. Some GPs refuse to talk to carers directly, citing confidentiality and refusing to acknowledge carers as equal partners in care. Others, however, are willing to listen to carers’ concerns and include them in strategies to enable people with worrying symptoms to access information, advice and potential referral for assessment. Some GPs still believe that there is no point in giving someone a diagnosis of dementia because there is nothing that can be done.

These issues should be included in the strategy. We therefore suggest an additional action point on page 20:

**GPs to be reminded that carers are equal partners in care and have valuable information that can assist in determining the right approach for individuals who may need further assessment but who may be reluctant to seek it.**

Again, **we recommend consistent use of language** so suggest that the final bullet point on page 20 should read ‘Increase the number of primary care practices in Wales that are dementia inclusive’.

Assessment and diagnosis
We heard many stories from carers that suggest assessment and diagnosis depend very much on your age, where you live, who your GP is, whether your preferred language is Welsh and the capacity of the local memory service. Being able to speak in Welsh was important for those for whom it is their preferred language; however, some carers said that they would rather have a

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**Our GP is excellent. She always asks about me as well as my husband [who has dementia]**

Anglesey carer

**GPs should not just dismiss concerns about our partners. The sense that “Something is not right” needs attention. It boils down to GP training. What would it take to ask “How are you coping?”**

Anglesey carer

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When my husband was tested a year after his diagnosis the assessor spoke Welsh. My husband scored much better because the questions made much more sense to him.

Conwy carer
professional speaking in English who knew what they were doing than someone speaking Welsh who

The proposed increases in diagnostic rates are modest, with the risk of conveying the message that diagnosis does not really matter. Carers regard diagnosis as a gateway to other help and support. We suggest much more ambitious targets are needed.

Once the diagnosis is given, experience varied widely in terms of the information and advice provided and access to post-diagnostic support.

Many carers reported being handed a ‘dossier’ of leaflets and other information that they found overwhelming and which no-one helped them to go through and extract what was relevant to their circumstances. Often the folder was put away in a cupboard and forgotten about until needs changed and they then had to go through it all to find what was useful. What was emphasised by everyone was the need for a single point of access or a named person who they could go to for information and advice. Most of the people looked after by the carers we met had been diagnosed over a year ago, so they had not benefitted from the dementia support service introduced from October last year. Some had a CPN or a social worker who they could contact, but many felt very much on their own and described having to find their way through the health and social care system, often spending many hours on the telephone or searching the internet for information.

A central point of contact would be so helpful because it’s so stressful going through all the numbers in the leaflets – the Carers Trust, the Alzheimer’s Society

Anglesey carer

We include here comments about post-diagnostic support (rather than in the following section on Living Well) as we believe it is essential that a consistent offer of support is made at the point of diagnosis to both the person with dementia and their carer(s). We heard excellent reports of the ‘Caring and Coping with Loss’ course run by the psychology department at Bangor University and funded through the BCUHB. One group of carers who graduated from the course continue to meet regularly for mutual support. However, the course is not readily available and can only be offered to a small number of carers during the year; the group in Gwynedd had not heard of it and one woman in Anglesey has been waiting nearly three years for a place. This is clearly the ‘deluxe’ offer of post diagnostic support and there is a need for a more basic, structured programme that provides education about dementia and local services available for support and creates opportunities for people to think about financial planning, making a will and their future housing needs in the light of the diagnosis. Only a handful of carers had had this opportunity but those who had found it extremely helpful. There is strong clinical evidence of the benefits of post-diagnostic support and it is disappointing that none of this research is cited in the draft strategy.

They want to increase the rate of diagnosis from a low percentage to something not much higher. How aspirational is that? A diagnosis can bring huge relief and should open the door to post diagnostic support

Anglesey carer

Leaflets are no good – you need to be able to talk to someone

Gwynedd carer

I was lucky. I was offered the ‘Caring and Coping with Loss’ course almost immediately after my wife was diagnosed. It was brilliant and really helped me cope with the emotional turmoil.

Anglesey carer

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Anglesey carer
For these reasons, we find the bullet point on page 26 concerning access to carer education and support too weak. **We recommend that health boards and local authorities should be required either to provide this directly (rather than facilitate access) or to commission it from the voluntary and community sector.**

Few carers had been offered a carer’s assessment; one person had demanded one when she ‘went into meltdown’. The statutory duties of local authorities and health should be reflected in the action points. We suggest:

**Local authorities to ensure that carers are offered an assessment of their own support needs at the point of diagnosis and other key transition points, such as admission to hospital of the person they care for, and that for those eligible this is translated into a support plan.**

**Living for as well as possible for as long as possible with dementia**

Carers described the difficulties of trying to organise help when their needs changed. Finding the right person to talk to could be frustrating and time-consuming if they did not already have a CPN, social worker or dementia support worker. District nurses were cited often as playing a significant role in referring people for further assessment or additional help. Many carers talked about the difficult role they had to perform, which they had not chosen and for which they were ill-prepared.

Few carers had been offered a Direct Payment, personal budget or support budget and many did not know that they were possible. For some carers such a facility had made a significant difference to their lives, making it possible to arrange flexible support at the times that suited them best; Anglesey council were particularly commended for their approach and the support provided to make the necessary arrangements. Others were clear that they did not want the additional responsibility on top of all the other matters they had to attend to in caring for someone with dementia.

![We’ve just lost our CPN because she only works with people with early onset dementia and my husband is 69 now. It’s hard because we’ve built a really good relationship with her and she knows his needs.](image)

![There’s not enough designated care for people with early onset dementia. We know a woman who had her 50th birthday in day care but she didn’t want to remain in the service because “they’re all old”.](image)

Carers of younger people with dementia described the lack of appropriate support for their relatives, who were often expected to join in activities or use services geared towards much older people. Where they did receive specialist CPN support, this would usually cease when the person with dementia became an ‘older person’ and had to transfer to another part of the service. Carers also highlighted the protracted time that it could take to get a diagnosis for younger people.

Many carers were keen for those they looked after to stay active and benefit from stimulating activities. If they could find such opportunities, often carers would accompany the cared for, but some also took the opportunity to get some time for themselves or to catch up on necessary tasks such as shopping or going to the bank, that could be more difficult or time-consuming if they had to take the person they looked after with them. Carers described stumbling upon these activities by...
chance – they were not offered routinely by service personnel and may not feature in the information packs issued at diagnosis.

Transport could be a problem, however, and carers who could drive regarded themselves as fortunate. Even so, getting to activities, especially in rural areas, could take up significant time.

The wider community can play a key role in enabling people with dementia and carers to participate as active citizens. We suggest the text on page 30 should read ‘Communities need to be encouraged to include those living with dementia....’

Carers were unanimous that being able to meet together to share experiences, get things off their chest and have a laugh together was invaluable, yet few had the opportunity to do so. Carers organisations in North Wales are generic and provide little, if anything, specific for carers of people living with dementia. Provision by the Alzheimer’s Society is patchy. Dementia cafes are aimed at the person with dementia although carers are encouraged to attend too. Those who attended our sessions to respond to this consultation found them immensely helpful, learning new information from each other (such as eligibility for a discount on council tax) as well as being able, in a safe space, to be honest about their circumstances and how hard caring could be at times. Yet the draft strategy is largely silent on peer support for carers in their own right, without those they care for being present too. A small amount of investment would reap benefits in terms of the mental health and well-being of carers, increasing their resilience and enabling them to continue caring for longer.

We therefore recommend that the strategy recognises this need (perhaps on page 30) with an action point:

Local authorities and health boards to ensure that peer support is made available for carers of people living with dementia, in their own right.

We are concerned that the draft strategy conveys confusing information about life story work (page 31). There is a difference between helping people create their own life story (in whatever format suits them), which remains theirs to share with whom they wish and during which establishing rapport and listening to the story are as important as the finished product; and producing personal profiles with key information about individuals that can assist staff to provide individualised care.
'This is me’ – a fact sheet – falls into the latter category whilst ‘Book of You’ is the former. A definition of life story work is helpful here:

*That life story work is, above all, a process that involves having helpful conversations to elicit, capture and use stories about a person, in order to promote their personhood and their well-being and keep them connected with family, friends and communities.*


We suggest that the action point should be amended and separated to read:

**People with dementia are enabled to create their own life story to promote their personhood and keep them connected with family, friends and communities.**

**People with dementia and carers are encouraged to create a ‘pen picture’ of their needs and preferences, such as ‘This is me’, to assist staff to provide individual care.**

In stark contrast to the aspiration of flexible, individualised ‘wrap around’ support services (pages 33 and 37), carers told us of the reality of trying to secure services that were flexible enough to meet the needs of those they looked after. One man described how the ambulance transport to take his wife to the day service arrived at 8.30 in the morning – half an hour before the paid carers arrived to help her get washed and dressed. The ambulance staff could not come back later, so he took her himself in the car. His unwitting ‘cancellation’ of the transport meant that it did not arrive to bring her home in the afternoon and he had to go and fetch her. He did not know this until the day centre rang him to ask why he had not arrived to pick her up.

Carers expressed concerns that home care staff are poorly paid and often have little training. Despite this, carers found most of them to be well-meaning and doing a good job. There were fears, however, that more and more is being pushed onto family carers because of the financial difficulties of local councils.

Whilst carers commended the reference to the importance of involving people with dementia and carers in the design and planning of services (page 33), they were dismayed that there is no action point associated with this and no detail about how and at what level people should be involved if they wish. All too often, involvement – or more likely engagement – is ad hoc and tokenistic, such as including one or two individuals in a standing committee or working group, without preparation or support, or a formal consultation exercise concerning a specific service change.

Examples of involving people with dementia and carers include:

- Training staff
- Recruiting staff
- Speaking at conferences

*My husband can be very stubborn. He’ll decide he won’t eat certain foods, so the home carers can’t get him to eat anything and they’ve stopped trying. I know how to handle him, but the staff haven’t got the time to spend with him.*

Anglesey carer
➢ Meeting with health board and social services managers on specific issues
➢ Having a seat at the table at planning forums/project groups
➢ Focus groups in specific service settings to give feedback

Only a few carers had had the opportunity to get involved; one example given was Caniad, but the carer concerned found himself to be the only one present who was looking after someone with dementia. Some had offered their time and expertise but had had no response. One carer was asked to join a carers reference group for the health board but had heard no more since the original request nearly a year ago. Carers asserted strongly that they needed the opportunity to make their voices heard alongside those of the people they care for and were keen for tide to help them do so.

We recommend an additional action point on page 33:

Health boards and local authorities to publish arrangements for involving carers of people with dementia in service planning and design and for seeking systematic feedback on the effectiveness of their services, using a combination of face to face, on-line and written methods of communication.

Finally in this section we heard from carers about the difficulties in finding your way through the system and knowing what you are eligible for. Whilst some professionals were helpful, some were given inaccurate or misleading advice. Most carers relied on the voluntary sector agencies to guide them through and help them fill in forms. Age Cymru, Carers Outreach and the Citizens Advice Bureau were all cited as offering practical help to complete applications and to explain what was available.

The need for increased support in the community

We heard several examples of professional paid staff, including those working in specialist dementia services, being unable to manage people with dementia in their services, yet they expected family carers to come and rescue them and to cope without additional support! This raises serious concerns about the training of support staff, including those who are professionally qualified, and their understanding of the needs of people with dementia and their carers.

I had an email with Terms of Reference and promising contact – then nothing – even though I sent emails asking what was happening
Anglesey carer

I applied for Attendance Allowance for my wife and was told it would affect my other benefits, so when I got it I told the benefits office I did not need them. Now the CAB is helping me put things rights again.
Gwynedd carer

My partner couldn’t carry on attending the day care because of behaviour problems/distressed behaviour. The Welsh group at Llandona made us totally welcome – it’s run by social workers
Anglesey carer

My mother used to go to Bryn Beryl [in Pwllhelehi], but the staff rang me one lunchtime and said ‘Can you come and get her please – she’s being disruptive!
Gwynedd carer
We heard some very positive stories from carers of the people they cared for being admitted to acute hospitals, demonstrating that even in busy A and E departments and in-patient wards it is possible to provide individualised care that takes account of the particular needs of people with dementia and their carers. They also reported that they felt involved in their care, one carer describing how she was able to stay with her mother throughout her stay in A and E and her eventual transfer to the medical ward, where the carer was made equally welcome.

However, we also heard of experiences that were not so good. These echo those described in Dignified care? The experience of older people in hospital in Wales (Older People’s Commissioner for Wales 2011).

Some carers described their frustration at being disbelieved that their relative had dementia!

Some hospitals have adopted the Butterfly Scheme¹ – yet some carers reported that this was not evident on the wards and staff did not seem to know what the carers were talking about when they tried to discuss this with them. In their experience the scheme had little impact on the quality of the care that their relatives received whilst in hospital and despite their best efforts, carers were not able to secure individualised attention based on the dementia of the cared for person. So although the scheme had been adopted at a strategic level, its merits had not been communicated to staff and implemented on the wards.

It is disappointing that the only initiative cited in the draft strategy under ‘Good care in hospitals’ is ‘This is me’. Although the Alzheimer’s Society offers many useful products, it is not the only organisation active in this field. Other examples could be commended and encouraged, such as the Butterfly Scheme and John’s Campaign², both initiated by carers as a result of poor experiences of acute hospital care for the people with dementia they cared for.

We consider that the action point on 39 is inadequate – what does ‘dementia-supportive’ mean? Again, the use of language is confusing. We suggest instead:

All health boards to identify which quality measures they will implement to ensure that working practices on hospital wards include the role of carers as equal partners and reflect the needs of

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¹ A scheme to identify people with dementia in hospitals; see http://butterfliescheme.org.uk/
² John’s Campaign for the right to stay with people with dementia and the right of people with dementia to be supported by their family carers: see http://johnscampaign.org.uk/#/
people with dementia, and how they will monitor their effectiveness. Examples could include ‘John’s Campaign’, the ‘Butterfly Scheme’ and ‘This is Me’.

We are surprised that the section on acute hospital admission makes no reference to delirium other than in the action point on page 40. This is a serious medical condition. Two in ten in-patients have a period of delirium and the risks increase for older people, those with dementia and those with memory problems (RCPsych Factsheet, 2012). NICE guideline CG103 (2010) sets out specific guidance and evidence based practice which we suggest should be referenced in this strategy. The involvement of carers as experts in the care of the person affected is crucial – they know the person best and can help staff identify changes in behaviour and mood associated with delirium. We recommend an action point specifically related to delirium:

**Health boards to ensure that the NICE Guideline CG103 (2010) relating to the diagnosis, prevention and management of delirium is adhered to in hospital settings**

Respite care was cited by carers as one of the most important services that can help them continuing to care, yet is the most difficult to access. Often the only offer is a place in a residential home which may not be best equipped to care for the person’s individual needs. Some carers stated that because their loved one refused go into a care home, they had no prospect of a break. Others described the difficulties when their relative returned home disorientated and distressed; it could take several days to settle them down again, sometimes clothes were missing and occasionally they came home with worrying bruises or in a poor state of personal hygiene. Some carers were able to save up their home care hours so that they could have a whole day out, knowing the cared for person was being looked after, but this flexibility was not always allowed by the local council. Overnight and evening care at home was almost impossible to access.

Some carers described the difficulties experienced when their relatives needed to move into care homes. Finding information and knowing whether a particular home was suitable or not were challenging. Word of mouth and personal recommendations were helpful, but a shortage of provision means that the better homes are in high demand so getting the home of your choice is a struggle. Some carers had better experiences of others of being included in the care of their relative.

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*When my husband went into respite I was not contacted/ they did not ring. When I collected him, there were finger bruises on his arms and hands. They had clearly locked him in a room and he had hurt himself banging on the door to get out. Regrettably, I didn’t do anything – but then I didn’t know what to do*

Anglesey carer
We suggest that the section on care homes in the draft strategy should include reference to the benefits of life story work (see our comments on page 8 above).

We are surprised that there is no reference to the learning from ‘In Search of Accountability: A review of the neglect of older people living in care homes investigated as Operation Jasmine’ (Flynn 2015), in particular the importance of listening to family carers and involving them in the care of their relatives should they wish to continue this role. We suggest that the specification for the ‘Directed Enhanced Service (DES) – or Direct Enhanced Service? – should include this requirement.

It is dismaying for carers that there is no reference at all within this document of continuing health care. Both during this consultation exercise and in a previous piece of work for the BCUHB (Strategic Review of Older People’s Mental Health Services Flynn and Eley, 2014) carers described the difficulties accessing continuing health care funding for their relatives: the tortuous process they had to go through; the lack of information and support available to guide them through the process; and their concerns that the money was not always well spent.

The section on End of Life Care is welcome, as dementia is not always recognised as having a terminal phase. Some people with dementia may not be able to explain that they are in pain, their agitation being assumed to be as a result of their dementia, and so may be sedated rather than offered pain relief. We suggest that the draft strategy should highlight the need for medical and nursing staff in acute hospitals – not just in specialist dementia services – to be aware of the needs of patients with dementia at the end of life.

We are surprised that there is no reference to resuscitation either here or in the section on admission to hospital; some carers described the thoughtless and clumsy ways in which the subject was broached by medical staff.

We note that that there is no reference to the impact of bereavement on carers or the need to offer further support once the person with dementia dies. We cite here the impact for Roy Tindall, a former carer, of the sudden death of his wife in hospital, after

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I researched 38 care homes online and looked at the CSSIW reports. It takes a long time for me to trust services, e.g. the agency staff in one home told me that he had had lunch by 12.30 – no way! He has always been a slow eater – one of the grandchildren takes after him. I managed to negotiate 1:1 support for two months because of the high risk of him walking around, but this is expensive. It’s less challenging now that he uses a wheelchair.

Anglessey carer

Where my husband is now there are carers in every room. We took a risk and it turned out so well. They are so caring – the room was newly re-carpeted and there was a new bed. I always feel welcome and they know they can get in touch at any time.

Anglessey carer

I had to fight really hard; the process is awful. Sometimes you have to resort to litigation which nobody wants to do.

Gwynedd carer

When my wife went into hospital, the opening gambit of the doctor was “our policy is that we don’t resuscitate...” How crass is that!

Anglessey carer

We note that that there is no reference to the impact of bereavement on carers or the need to offer further support once the person with dementia dies.
many years of looking after her. Not only did he have to cope with his bereavement – but everything else stopped!

I came home from the hospital and it was as if everything had stopped. I rang all the statutory bodies that day to inform them and a hurriedly prepared list of everybody else that I felt was appropriate.

I heard nothing back. Nobody called. It is as if I was no longer of interest.

59 years of married life, five plus years of caring. My 24/7 job had just ceased with immediate effect. I had no other life, nothing. Never had I felt so low.

All that happened was that I received demand letters for repayment of relevant monies that had continued despite my phone call to let them know of her death.

My one saving grace was that I had a voluntary ‘Befriender’ who helped me to manage my bereavement. She became my one source of support in those initial painful days and months. It cannot be stressed too highly how important a role she played at that time but I now hear that funding for this invaluable service is being stopped. I consider myself lucky that my ‘befriender’ is going to continue to see me when, at even this time after bereavement, her visit is still the highlight of my week.

There is an obvious need that every carer, when their life is changed so dramatically, and in my case and others so suddenly, should have a professional or voluntary befriender as a statutory right as part of the welfare system. The cost by comparison to overall welfare cost would be minimal but the benefit will be inestimable. The trauma of losing someone that I had cared for is far in excess of many traumas that in other circumstance would receive immediate and urgent professional care.

Roy Tindall

Sources of Information

Please include the following:

The Life Story Network promotes the use of life story work to enable people to retain their sense of self and stay connected with their families, friends and communities. It offers various training programmes, including ‘Family Carers Matter’ designed to enable carers to reconnect with those they are caring for. Further information is available at: www.lifestorynetwork.org.uk

tide – together in dementia every day is a UK wide involvement network for carers of people living with dementia. Membership is free. Further information at: www.tide.uk.net

Ruth Eley

Director and vice-chair, the Life Story Network CIC
WHAT WOULD MAKE IT EASIER FOR YOU TO LOOK AFTER THE PERSON YOU CARE FOR?

A single point of contact or a named person to go to for advice and information

A structured programme of post diagnostic support for you and the person you care for

Opportunities to meet with other carers (peer support)

Respite care that gives more choices than admission to a residential care home

Overnight and evening care

Staff working in hospitals, GP surgeries and social services who understand about dementia and what it means

Being treated by these staff as an equal partner in care

Recognition of your role as a carer and your expert knowledge of the person you look after

Information about local services and what options you can consider e.g. different sorts of housing

Staff who speak Welsh