



Gofal Cymdeithasol **Cymru**
Social Care **Wales**

Supporting people with dementia to get out and about

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It's important that people with dementia continue to enjoy being an active part of their community.

An introduction to supporting with people with dementia to get out and about

[View transcript](#)

GINA SHAW:

Co-chair of SURF

[00:00:01] He's going to get the Diddy Men in.

TOMMY DUNNE:

Co-chair of SURF

[00:00:05] An old Ken Dodd joke:

[00:00:06] Your brain's a wonderful thing; starts working the minute you're born and doesn't stop until you get to speak in public.

GINA SHAW:

[00:00:16] And he uses that all the time.

TOMMY DUNNE:

[00:00:17] I do [laughter].

[00:00:21] A Window of Opportunity

TOMMY DUNNE:

[00:00:28] When you think that a third of people with dementia in this country live alone in the house, we want to come out into shops, enjoy the aromas in the cafes and we

need transport to actually get us here.

[00:00:40] We're actually working with the bus operating companies who've asked us to go into the depots and talk to the bus drivers so that they will have an understanding.

GINA SHAW:

[00:00:48] Yes, so that we can encourage people to be able to go out on their own on buses and feel safe.

[00:00:55] **Goodison Park Stadium**

PRESENTER:

[00:00:58] SURF is a Liverpool-based group made up of people living with dementia, carers and professionals who meet once a month to drive forward changes in local services and the community.

DR SARAH BUTCHARD:

Clinical Psychologist, Mossley Hill Hospital

[00:01:09] I've worked in dementia services for a while and I've always felt that people can live positively with dementia.

[00:01:14] But people with dementia have got the best view of anyone of what people with dementia need.

[00:01:19] If we really listen to what it is that they're bringing, we can truly develop the services that are going to meet their needs and enable them to have the best quality of life that is possible.

STANLEY LIMBERT:

Member of SURF

[00:01:29] It makes a big difference. It certainly makes a difference to me as an individual, because I'm getting more of an insight and I have some influence.

PART & DAWN:

Carers & members of SURF

[00:01:36] We work on practical solutions to problems that we all encounter.

[00:01:41] We just want somewhere where we can go and express our feelings and get things done.

GINA SHAW:

[00:01:47] We asked members of SURF what shops and business that they might like us to look at.

[00:01:53] What we did was contact all of those places and invite them to an event here at the Town Hall.

TOMMY DUNNE:

[00:01:59] The people that came were top managers, people who could actually change policy within their own shops.

GINA SHAW:

[00:02:04] It's empowering people living with dementia, and their carers, to be able to feel that they can go into these premises, into these businesses and be treated well.

[00:02:17] We know that dementia is a progressive condition but we're making the most of it while we can.

TOMMY DUNNE:

[00:02:22] We know we haven't got ten or twenty years with Gina but we're realistic.

[00:02:28] We know we've got a window of opportunity and the chance through the SURF people to actually help.

[00:02:32] One of the best things I ever heard one fellow say to me was "You've inspired me, you've given me hope," and I thought that's what we want.

SURF Liverpool is one of over 50 groups led by people with dementia around the UK who are working hard to achieve change in their communities

www.dementivoices.org.uk

70 per cent of people living with dementia say they've stopped doing the things they used to enjoy because of lack of confidence. More than a third feel lonely and this rises to nearly two thirds of people who live alone.

[Dementia 2013, The hidden cost of loneliness, Alzheimer's Society, 2013](#)

Clearly, something needs to be done to support people to get out and about.

Plan ahead before a trip

Simple changes and careful planning can make a big difference:

- Have a friend or family member accompany the person.
- Some charities have befriending services that can help with the same role.
- If swimming changing rooms are becoming challenging because of disorientation, or the person struggles to get themselves dressed, enjoying the activity with a friend could make the difference between going or not going.
- Perhaps a member of their church could collect the person so that they can continue to attend their place of worship.
- Choose quieter times. Avoid mother and baby groups, which may be overwhelming. The supermarket will be quieter on a Tuesday morning than a Saturday afternoon.
- An out-of-town store with easy parking may be better than a high street shop that involves a bus ride.

Look for dementia-friendly activities

Many clubs, shops and groups are becoming 'dementia friendly', meaning staff will be aware of the challenges of dementia and can offer appropriate support.

These might include:

- Swimming sessions

- Dementia friendly choirs, which have the additional benefit of meeting new people, having fun together and sharing experiences and being socially active.
- Dementia friendly film screenings, where the lights stay on and there's a comfort break during the film.

[Glenda Roberts talks about going to a dementia-friendly screening of White Christmas](#)

All museums across Wales are dementia friendly, and free! And there are many dementia cafes. Is there one near you?

[Find a dementia café near you](#)

Don't try to do too much at once

It's sometimes better to do one thing and enjoy it, rather than trying to do too much at once.

Going swimming with a friend may be a success but going for a pub lunch after it and then popping to the supermarket on the way home may be too tiring and the enjoyment of the swim is lost.

While it may not be you accompanying the person to their preferred clubs or trips, knowing what's available in your local area can make a huge difference.

Sometimes a word of encouragement and a point in the right direction is all the person will need.

[Dewis Cymru](#) is a great source of information for resources across Wales.

Balancing risk and well-being

There are risks involved in everything we do: cooking, gardening, walking or DIY. This is true with or without dementia.

In dementia care there's constant debate about how we support people with dementia to have meaningful activities that might involve risk.

Professionals and families often become risk averse and the consequences on a person with dementia's well-being and quality of life can be significant.

The main law which supports decision making is the Mental Capacity Act 2005.

The Act starts with an assumption that people have capacity to make decisions for themselves unless proven otherwise.

So if someone with dementia wishes to continue working with wood, they can, in the same way as you could make that decision. Even if that decision might be unwise.

'Positive risk enablement' is the way forward.

This approach acknowledges and identifies risks and puts measures in place to minimise them without eliminating risks all together.

It acknowledges there are consequences to physical and mental health by not taking part in meaningful activities and that to truly live well with dementia, people will take risks.

Positive risk taking is often a balancing act. Simple actions and the use of assistive technology may help achieve the balance.

For example, taking a mobile phone with emergency contact numbers while out on a walk may help the person with dementia feel more confident that help is at hand if needed, and give the family carer the confidence to let them go.

Using public transport

Every person who's diagnosed with dementia must tell the DVLA, who'll assess their ability to drive safely.

For many, the reality is they'll lose their licence.

This can be a difficult time for a person living with dementia and can lead to dependence on others or on public transport to get around.

The impact can be heavier in rural areas, with poor public transport contributing to increased isolation.

[Dementia in rural Wales: the lived experience](#)

However, many areas have community transport services for people who find it difficult to use public transport.

These include door-to-door transport and trips to shopping centres.

[Search for community transport services in your area](#)

The Dementia Action Plan for Wales (2018) has committed to supporting people with dementia to use public transport by ensuring that

- transport planners and operators consider their needs in major contracts like the South Wales Metro and rail franchises
- public transport staff are trained about the barriers people living with dementia face when using their services.

[The Dementia Action Plan for Wales](#)

Case studies about supporting people with dementia to get out and about

[How the Me, Myself and I Club has helped Mrs T regain her confidence](#)

PDF 3MB

[View transcript](#)

GAVIN WATKINS:

[00:00:04] When I was diagnosed with early onset of Alzheimer's in Cornwall, and the psychiatric nurse used to come and give me the tablets,

[00:00:13] he would phone up once a month and then after he'd finished work and say "Everything okay?"

[00:00:19] We'd say "Yes, no problems".

[00:00:22] “Okay I’ll be round with your prescription”, and when he turned up it was “See you next month”, and that was it.

[00:00:29] And I saw a GP once a month there. Nothing at all, no support whatsoever.

[00:00:36] We came here and because we moved areas I had to go and see a specialist and they suggested I went to these memory cafes because I was just vegetating and doing absolutely nothing.

[00:00:48] I had no conversations whatsoever, it was a yes and no, if you could get that out of me.

[00:00:55] I started going, I didn’t like it, I didn’t want to go again after the first week.

[00:01:01] The second week no so bad, now I just can’t leave them alone, I’ve got to go to them, I’ve got to be there every week if I can.

[00:01:11] We’re lucky, we have a vehicle, but there’s people out there that haven’t and it’s absolutely ridiculous the amount of people that can’t get there.

[00:01:21] There’s over 9,000 that aren’t getting help, what they need.

[00:01:27] The services are out there, the memory cafes are there, but it’s being able to get to them is the biggest problem we’ve got.

[00:01:34] I’ve set up a charity, Blaenau Gwent Dementia Community, to help people in Blaenau Gwent with dementia to get to these places because of transport is our biggest problem.

[00:01:34] It brings you out into the community.

[00:01:50] You go to chat, you talk to other people with the same problems as yourself and other problems.

[00:01:58] The carers are able to talk to other carers so they know they’re not left on their own, and they’re not the only doing this sort of work.

[00:02:07] What we’ve got to remember is every one of us is different, we’re not all the same, we all need different treatment.

Useful resources

Find out more about supporting people with dementia to get out and about.

[Video about how a dementia community forum has worked with a local bus company to help make the service dementia-friendly](#)

[View transcript](#)

Aunty Glenda's Project

Bryn Beryl Hospital

Hafan Ward

MORGAN:

[00:00:16] What I remember most is going to Bryn Beryl to the Hafan Ward.

[00:00:25] I enjoyed being able to play games and things like that with the people who had dementia to get to know them a bit more.

CHERYL WILLIAMS:

[00:00:31] It's important for children to come to understand a little bit more about dementia so that we create communities that understand dementia from the very beginning.

[00:00:44] And as children understand more about the condition, they can then be more tolerant of people who are living with dementia in their own communities.

[00:00:55] Aunty Glenda's Project

CHERYL WILLIAMS:

[00:00:58] Or a memory or a skill. You know, you've written there now, everything that the brain helps us to do, well, every one of these lights represent something like that, and what dementia...

MORGAN:

[00:01:13] Everyone in the class got a card with a job that you are used to doing in a day,

[00:01:17] and then she had red wool and she connected them to each job.

[00:01:23] And then when you become more affected with dementia, it's broken and then they forget things.

[00:01:29] Perhaps they forget going to brush their teeth and they go straight on to doing something else.

CELT:

[00:01:38] When you cut one strand it was like something going out of your memory.

CHERYL WILLIAMS:

[00:01:43] So as we get older, not everyone will get dementia. It's not a natural part of getting old.

[00:01:52] Well, Dementia Friends began in 2014 and it comes under the Alzheimer's Society. [00:02:01] It's supported by the Government as part of the campaign to get communities that are more tolerant of people who are living with dementia.

[00:02:12] What do you see in that picture?

BOYS:

Two people talking.

CHERYL WILLIAMS:

[00:02:15] Two people talking. What else can you see in it?

[00:02:20] The shape of a cup in it, isn't there? A different shape, what we see there.

[00:02:28] It's an opportunity to start the conversation about dementia so that we try to get rid of the stigma and the fear that's associated with it as well,

[00:02:39] and by having Dementia Friends people can understand a bit more about the condition, about the illness, and be a little more supportive of people who are living with

dementia.

[00:02:52] Thirty, twenty, up to ten years old, who remembers their first day at school?

GIRL:

[00:02:57] My first day in this school, I remember sitting on the mat and trying to remember everyone's names.

CHERYL WILLIAMS:

[00:03:02] Trying to remember everyone's names.

PHOTOGRAPHER:

[00:03:11] Big smile now, one, two, three.

12 October 2016

Hafan

Bryn Beryl Hospital

EDWIN HUMPHREYS:

Staff Nurse, Project Co-ordinator

[00:03:22] Thank you for coming. This is where we're working, in T? Hafan isn't it, and it's like a Day Club, a Day Club for people to come from home if they want to come in to see us.

[00:03:35] After Cheryl visited the school, we had an open day in the Hafan Unit.

[00:03:39] The Hafan Unit is where we go to introduce the children to people who suffer from dementia.

[00:03:46] We're a Unit that holds activities here. It's day care that we offer and we're open from nine until five.

[00:04:05] And the children were playing games with people all day, and they were having a lot of fun together.

[00:04:10] That broke the ice.

[00:04:11] The children could see that these people were not as bad as all that, and they're not some very odd people, they're just people like you and me, and that worked very well.

MORGAN:

[00:04:33] Everyone there had interesting stories.

[00:04:55] 16 November 2016

MARI IRELAND:

Community dementia nurse

[00:04:59] I had no idea what dementia was at the time. We've come a lot further now haven't we, with time? And a lot of people know about dementia I think, don't they?

[00:05:08] I work as a community nurse in south Gwynedd, working with young people with dementia and then I know Edwin through my work and he contacted me to do some work with schools through the medium of Welsh.

GLENDIA ROBERTS:

[00:05:25] Because I'm young, Young Onset Dementia they call it, that's what people my age get.

[00:05:33] I was forgetting to send birthday cards, I was ... I had, perhaps a dental appointment, I would forget to go to the dentist's surgery.

[00:05:44] Oh, I did a lot of tests and then they found that I had dementia.

[00:05:51] And when this was happening, I was worried, I was very worried because I didn't know what was the matter.

[00:05:58] I knew that there was something the matter but I didn't know what.

[00:06:04] And then when they said "Yes, you've got dementia," it was a relief because, well, I knew what I had to do, I knew what I had to deal with.

MATH:

[00:06:20] To start with, she was forgetting what everyone wanted, what everyone liked for tea and then she started forgetting more important things.

GLENDA ROBERTS**(Aunty Glenda):**

[00:06:31] Living with dementia is difficult. There's nothing easy about it.

[00:06:37] Your life changes, but with the support of the family, and somebody says "Come on, you can do that," and then I haven't just sat in the house, I carry on going.

MARI IRELAND:

[00:06:51] What was very obvious, from sitting with the children after they heard Glenda talking, was the big difference in the way they responded to dementia.

JAC:

[00:07:03] Forgetting the names of her friends.

MARI IRELAND:

[00:07:08] It's obvious that they listened and took a lot of information on board, but what was really, really lovely was when one little girl said...

GLENDA ROBERTS:

[00:07:18] "I was afraid of dementia but I'm not afraid now." And that was a really lovely thing for both of us.

MARI IRELAND:

[00:07:26] And that was the best thing that could have come out of the project in terms of what I felt about what we were doing and also how Glenda felt, I think.

GLENDA ROBERTS:

[00:07:37] Yes, I like making cakes and things, so I still make cakes, I still do everything myself in the house, but Mari is an important part of my life and my family.

TEACHER:

[00:07:55] Right, that's it, Glenda [clapping sound].

[00:08:08] 23 November 2016

CHILD:

[00:08:09] Anni LL?N came to write a poem with us.

ANNI LL?N:

[00:08:18] Today, I've been doing a workshop with Year 6, a workshop with words and we were creating, talking about feelings and emotions and the fact that everyone has feelings;

[00:08:30] everyone feels a mixture of feelings and emotions.

[00:08:36] So, what the children were doing was trying to put every emotion into a little verse.

CHILD:

[00:08:42] Fantastic.

ANNI LL?N:

[00:08:43] Fantastic!

MORGAN:

[00:08:44] We had to think about a feeling that people with dementia would have and then we had to create a poem about that.

ANNI LL?N:

[00:08:50] Who's finished? Okay then.

CELT:

[00:08:53] I feel confused

Grey like a cloud

It happens when I hit my head against the wall

The sound of children on the road shouting

Talking

Confused.

ANNI LL?N:

[00:09:06] Very good.

[00:09:07] And the idea that they consider that it doesn't matter what your situation is – you might be ill, you might be completely healthy, you might be unemployed, you might have very heavy work and be very busy –

[00:09:21] whatever your situation, everyone feels and treats their feelings in a different way and that's what connects everyone. So, that's what we did today.

[00:09:31] You've done excellent work and thank you very much for working hard with us this afternoon.

[00:09:40] 05 May 2017

TESS URBANSKA:

Artist

[00:09:49] We created *animations* today that were inspired by the poems the children had already written with Anni LI?n.

GIRL:

[00:09:57] A happy cloud flies in and about half way it's going to be sad because it feels confused and it starts to rain and the words, that are a little confused, run after it.

MORGAN:

[00:10:28] Every group gets a poem and then we had to make an *animation* to go with that and then, yes, that was very interesting and I didn't know there was so much work involved in *animation* before.

MARI IRELAND:

[00:10:42] The hope is, now that we've completed this project, that other schools will take up the reins and do something similar in their communities, or in their schools, to support dementia.

[00:10:56] Once children gain an understanding and learn about dementia, the hope is that then it is taken forward into families and to the communities in which they live in order to make life better for people with dementia, to create friendly communities and let people or allow people to work much longer in their communities, well and safely.

CELT:

[00:11:23] I think it's important to get to know how to treat people like that. They're no different to us. They're people too.

MORGAN:

[00:11:31] You never know to who it's going to come. It could come to anyone.

[00:11:36] The Poems

[00:11:38] Red like the school's polo shirt

I see a flash of lightning

I hear the sound of a train on the track

I'm unhappy.

[00:11:50] Blue like the sea bed

I see a snowman that has melted

It sounds like a trombone that's out of tune

I feel disappointed

[00:12:01] Pink like a butterfly

I see Father Christmas

I hear bells ringing

I feel happy

[00:12:09] Light like the sunset

I can see the ground opening

It sounds like a fire crackling

I feel jealous

[00:12:15] Green like the Wales field

I see fireworks

I hear popcorn popping

I feel wonderful

[00:12:23] Yellow like a flower

I see chocolate dancing

I hear autumn leaves crunching

I feel fantastic

[00:12:33] Red like the Wales field

I see a bull

I hear shouting

I feel angry

[00:12:44] Grey like a cloud

I see words bouncing

I hear millions of voices

I feel confused

[00:12:52] Purple like a bruise

I see nothing

I sound like a fart

I feel ashamed

[00:12:59] White like paper

I see stars

I hear dishes falling on the floor

I've had a shock

CELT:

[00:13:11] In the future, there won't be such a thing as dementia and you can find something to avoid the illness and to make them better, hopefully.

Song

[00:13:20] Thank you Aunty Glenda

You really are a friend to us.

Teaching us about dementia

Thank you very much from us.

[00:13:45] Thank you Aunty Glenda

You really are a friend to us.

Teaching us about dementia

Thank you very much from us.

Closing credits

Many thanks to

Glenys Roberts

Mari Ireland

Children and Staff of Ysgol Pentreuchaf

Staff and Group at the Hafan Unit

Dr Catrin Hedd Jones

Sean Page

Children and Staff of Ysgol Llywelyn

Bryn Hesketh Unit

Jane and David Lawson

Kerry Macdonald

Cheryl Williams

Anni LI?n

Tess Urbanska

Pant yr Hwch Children's Choir

Edwin and Ceiri Humphreys

Pant yr Hwch Studio

End

[The Me, Myself and I Club in Britton Ferry](#)

[Person Centred Support \(A charity that provides short breaks and befriending for people with dementia in north Wales\)](#)

Research links

Improve your practice by accessing the latest research findings.

We also have a page of [research on loneliness](#), chosen by Dr Deborah Morgan of the Centre for Ageing and Dementia Research (CADR) at Swansea University.

[What is the Relationship between Health, Mood, and Mild Cognitive Impairment? \(2016\)](#)

[Therapy through social medicine: Cultivating connections and inspiring solutions for healthy living \(2017\)](#)