

**#DementiaNWales** 

24 & 25 November 2015, St George Hotel, Llandudno, N Wales

## Dementia Education and Inclusion Meet-up

hosted by Chris, Jayne and Kate Roberts

Information and inspiration to create more informed, inclusive communities and improve dementia care and support in N. Wales

"I'm your average 53 year old man who cares about dementia awareness, but it has to be good quality awareness, it has to be about promoting education about dementia because it is starting to touch us all. Everyone is beginning to hear the word 'dementia' but not a lot of folk actually understand it and with over 850,000 people living with this illness in the UK we all need to know at least a little about it. You see



"I" have dementia, mixed dementia, vascular and Alzheimer's, but with the emphasis that I may "have it" but it certainly doesn't have me! Power is knowledge, knowledge is power!

It can affect everyone completely differently because the causes of one's dementia can be quite different. It's progressive which means it will gradually get worse, which is why an early diagnosis is good to have, to put help in to place and plan for the future - because with the right support and assistance it is possible to live well with it.

I look to the future now and never the past, I concentrate on what I can do, not what I can't. Dementia awareness, because I've become an expert by experience, but only in my own dementia because everyone is different.

I am an Alzheimer's Society **dementia champion** and host awareness sessions. I also speak at conferences and write about my experiences as it's important for people with conditions to be visible - we need more people doing this. Recent conferences include: the **Wales Audit Conference**; on behalf of **Dementia Alliance International** (I'm a board member) at the **Alzheimer's Disease International Conference** in Perth and at the **Alzheimer's Europe conference** in Croatia.

Now it's time to do something where I live, in North Wales. I'm involved in lots of stuff now, things I hope will make a difference, I only have a limited window to do this in and doing this in turn keeps my brain sharp which can't be a bad thing and must help, well I think it does.

I'm trying to make a difference while I can - if I can do this, what can you all do :)"



More about the Meet-up inside »

More information or to book please email: workingwithnotto@gmail.com

#### #DementiaNWales

## Working with our community...

We are responding to Chris' challenge - What can we all do? We can all do THIS. Using our definition of co-production:

'A group of people, working with each other from the start, as equals, to achieve a goal.'



Chris and Jayne are UK leads in Dementia research, awareness raising and champions. They speak all over the world sharing their stories and expertise on living with early onset dementia and its impact. They, and their connections, are a huge asset to North Wales. Now they want to do something closer to home and need all our help to make this happen. The meet-up agenda has been co-produced with Chris and Jayne to utilise their knowledge and connections to achieve specific aims.

We want to change how dementia and end of life care is delivered right now, and in the future. Where everyone is included and enabled to participate and contribute to the communities they live in. The outcomes and information collated will impact and influence wider groups of people.

We'll use visual-led inclusive methods developed during our ten WWNT 'meet-ups' to engage, have 'conversations that matter' and capture people's views. 'What matters' to people is at the centre, using what we have - an ABCD (asset-based community development) approach. Thanks to everyone for their support, now it is over to you... This is a co-produced independently-funded event. Please share and encourage people to come, promote the free citizen places and buy tickets.

- Pam Luckock & Fran O'Hara, Directors 'Working With Not To' Co-production Project

### Our main aims...

- To asset map the information, support and provision currently available for people with dementia, their carers and families. To collate the data into a research report.
- To identify **key issues for people with dementia**, their carers and families and potential solutions.
- To map a **Dementia Care Pathway** for North Wales, for the people with dementia, their carers and families.
- To build a learning community and database, which we hope will lead to a N Wales Dementia network. Also, an action research group.
- To train a group of people to become **Dementia Friends.**

- To build the understanding and confidence of people with dementia, their carers and families to become more visible and vocal citizen voices, advocates and speakers.
- To create a model design of a dementia friendly, inclusive event, and an agenda where everyone is included and can contribute.
- To promote Dewis with a team, stand and ipads to input data and identify needs and gaps in N Wales.



## DAY ONE: TUESDAY 24 NOVEMBER 2015

9.30am	Refreshments, exhibition viewing, quiet space time, Dewis
10.00am	Welcome, Chris, Jayne & Kate Roberts 'Creating inclusive communities, a place for everyone - what matters to us'
	We have invited Kate Swaffer to webcast with us from Australia.
10.30am	Jeremy Hughes, CEO, Alzheimers Society UK 'Dementia Friends'
10.45am	'Using what we have' asset-mapping dementia care and support in North Wales. Group discussion activity 1
11.30am	Break
11.50am	<b>'Dementia care pathway - Identifying issues &amp; gaps'</b> Group discussion activity 2
12.35am	Prof. Bob Woods, Bangor University 'Arts and Dementia'
12.50pm	Lunch, exhibition viewing, quiet space time, Dewis
1.50pm	Agnes Houston, Dementia and Sensory Loss
2.05pm	George Rook, patient activist 'In an Ideal World'
2.20pm	<ul> <li>First participant choice session: a choice of themed workshops, informal hosted table conversations, quiet space, exhibition, Dewis</li> <li>Young carers • Being a dementia champion/voice</li> <li>Dementia and the natural environment • Dementia choirs</li> <li>Dementia + transgender • Dementia faith /ethnicity</li> <li>Dementia and memory tasks/music • Dementia + sensory loss</li> <li>Late diagnosis • Dementia and care homes • And more</li> </ul>
3.20m	Break
3.40pm	Second participant choice session

#### Chris, Jayne & Kate Looking forwards together 4.45pm

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## DAY TWO: WEDNESDAY 25 NOVEMBER 2015

9.30am	Refreshments, exhibition viewing, quiet space time, DEWIS
10.00am	Welcome - Chris and Jayne Roberts 'Creating change together'
10.15am	Keynote speaker and Multi-sector panel presentation The current North Wales dementia care landscape
10.30am	Reviewing the asset-map of dementia care and support in N Wales - developing recommendations for action group activity.
11.20am	Break
11.40am	<b>'A dementia care pathway - Identifying issues and gaps'</b> Data review & creating recommendations for action group activity.
1.00pm	Event close - Chris & Jayne Roberts 'Looking forwards together'

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## WHO SHOULD COME?

Anyone who has dementia or is involved with dementia care and support in North Wales, service-providers, citizens,



professionals and 'experts by experience' have valuable knowledge to share.

Day 1 focuses on listening, learning and sharing, with as much of the conversations captured as possible. Day 2 focuses on reviewing the data/information captured, creating recommendations and a plan. All conversation should end in action, we want to MAKE A DIFFERENCE.

We would like as many people with dementia and their families and carers to come as possible, so your voices are heard and recorded. Working with Chris to create a dementia-friendly programme and meet-up. There are quiet spaces, smaller tables and comfy chairs for 1-1 conversations, choices about sessions to attend or not attend. The spaces will be clearly signposted, with refreshments available all day.

Please come and make the most of this opportunity to bring rapid, real and the right change for dementia care and support in North Wales.

We would like to thank all our speakers and everyone who has offered to host table discussions and support the meet-up.

#### CHRIS ROBERTS @mason4233

Living with mixed dementia, Dementia Friends Champion, Alzheimers Society Ambassador, Join Dementia Research Champion, Board Member Dementia Alliance International. <u>w: www.mason4233.wordpress.com</u>

Co-hosting with his wife and daughter **JAYNE & KATE ROBERTS** @jaynegoodrick

#### JEREMY HUGHES @JeremyHughesAlz

CEO of Alzheimer's Society UK. Campaigner for people with dementia. Believes social action can change society for better. e: Jeremy.Hughes@alzheimers.org.uk

#### GEORGE ROOK @george\_rook

Living well with mixed dementia. Promoting patient involvement and co-design. Influencer for change in healthcare. Chair Shropshire Dementia Action Alliance and a Dementia Friends Champion. <u>e: Georgerook51@gmail.com</u>

#### AGNES HOUSTON @agnes\_houston

Diagnosed at 57 with Early Onset Alzheimer's Dementia. Active member of the Scottish Dementia Working Group. Campaigning for best practice/ improving lives of people with dementia in Scotland and abroad. e: agneshouston@hotmail.com

#### **PROF. BOB WOODS**

Professor of Clinical Psychology of the Elderly at Bangor University. Co-Director, Dementia Services Development Centre Wales. e: b.woods@bangor.ac.uk

#### KATE SWAFFER @KateSwaffer

Advocate for, and living beyond, a YOD diagnosis. Meaningful dialogue about critical issues impacting a person living with a dementia diagnosis and their loved ones. w: www.kateswaffer.com

#### SUZY WEBSTER @suzysopenheart

Carer of her mother who lives with dementia, Expert by experience for CQC in England, works for Age Cymru on the My Home Life programme and proud new Trustee for @aliveactivities. <u>e: suzy.webster@agecymru.org.uk</u>

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## How much does it cost?

We have a range of ticket options.

- We have a limited number of FREE places. These are reserved for people with dementia and their families/carers and citizens who do not have funds to buy a ticket.
- PAID tickets fees:
  - Day 1 ticket = £85.00
  - Day 2 ticket = £35.00
  - Day 1 & 2 ticket = £120.00
- Fees from the PAID tickets will be used to cover the FREE tickets our aim is for 50% of attendees to be people with free tickets.
- If you're able to sponsor places or an element of the meet-up please let us know.

## How can I book a place?

Email Fran at <u>workingwithnotto@gmail.com</u> to request a place/s. All place bookings must be confirmed by us, we want as many citizens present as possible, and people from all sectors.

## How can I support you?

Share the meet-up, buy tickets, sponsor us, help out on the day and come and contribute...

## **Exhibition & Meet-up Book**

We have an exhibition area where you can hire a space and are producing a meet-up book where you can share your service/activity.

## Venue Information

The St George Hotel in Llandudno are working with us to make the venue and meetup as accessible as possible, particularly for people with dementia. They've offered us a reduced hotel room rates, quote 'Dementia Education and Inclusion Meet-up' when booking. If you are in a wheelchair or have any special requirements please let us know in advance.

For more information or to book please email: workingwithnotto@gmail.com Places are limited so please book early.













