

1st Steps in Dementia

Part of the Later Life Training Continuum

What are we doing with this information?

- We will provide the participating SURPs groups with a summary
- We are sharing it on the Later Life Training website to celebrate Dementia Awareness Week
- We will share it with those people we train and work with, including leaders and teachers, leisure, recreation, health and fitness centre managers and others who promote physical activity
- We are sharing it with the Alzheimer's Society and other organisations

Further information

Later Life Training is a member of the Dementia Action Alliance and is working towards becoming Dementia Friendly.

**laterLife
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**People living with dementia
and physical activity**

“Having a conversation”

**laterLife
training.**

DEMENTIA

Introduction

Taking part in physical activity can make an important contribution to the lives of people living with dementia, (PLWD) but they face many barriers and challenges in doing so. There is some research that helps us understand how a lack of knowledge about dementia from the general public, a lack of formal and informal support and a lack of appropriate activities are part of this challenge. Such research often provides an evidence base with generalised conclusions and advice that provide a helpful starting point to understanding. But to get closer to determining the needs of the individual and be Person Centred in planning physical activity opportunities for PLWD, there is a need to learn of the specific needs, experiences and motives of individuals. This requires those who provide physical activity opportunities to "have a conversation" to ensure their approach is Person Centred.

What we did

Working with local Alzheimer Society Service User Review Panels (SURPs) in England we undertook a series of informal conversations with PLWD on physical activity participation. We listened to their views, interests and experiences and the challenges they face in taking up and/or continuing a range of physical activities during their dementia journey. This was with the purpose of revealing the range of different examples of those interests and experiences

Our conversations were about

- What sorts of activities do you enjoy doing and why?
- Do you have any "Magic Moments" to remember?
- What is the best thing about being active?
- What are the biggest challenges you face in taking part?
- How can leaders, teachers and coaches provide better opportunities for people living with dementia?
- What else could be done to help you?

The examples of the discussions listed are not presented as research findings or a comprehensive survey of the views of PLWD, but they do illustrate the diversity of their thoughts, attitudes and experiences



Commentary

These conversations help us understand that

People living with dementia are like everyone else in the variety of opinions and attitudes they have towards physical activity.

Physical activity is not always recognised as a concept. Many conversations dwelt on structured and organised activities rather than activities such as walking or gardening.

Participants recalled many experiences from way back in time and these experiences impact on beliefs and attitudes.

These experiences often revealed emotional connections and sensations, eg. pain, pleasure, friends and places.

But the challenges they face are different. Participants spoke about a loss of skills, the need for support and understanding and a concern for the unknown, what might happen in the future.

We did not involve young people or those with early onset dementia and although family care-givers had offered support to participants in preparing their thoughts, they were not directly involved in these conversations.

Our thanks to the members of the SURPs in Portsmouth, South Shields, Gateshead, Weston Super Mare and Bradford who took part and their supporters who assisted in facilitating these discussions.

Thanks also to Kim Nguyen, Project Support Officer - Engagement and Participation at the Alzheimer's Society for her support in this work.

What else could be done to help you?

Need to know that I'm not doing too much – perhaps leading to injury



Good ratio of instructors and helpers

Make it easier for us to know what choices we have, what's available locally, it's very difficult to find out

One thing at a time, keep it simple but not childish

Would help if I could have a buddy to go along with me who was also interested and would join in with me



Ensure all staff have done some sort of dementia awareness and understanding

Provide information and guidance on activities and exercises people can do in the comfort of their own home

Want walking to be interesting, things to see and learn about as well as just being healthy

It would be good to have a clear point of support/help and to know who can help me



What sorts of activities do you enjoy doing and why?

Something to look forward to - meeting people



Something that gives me satisfaction and makes me feel healthy



When we are singing, getting up to move

Challenge of the new - meeting people

Things I did as a kid, boxing and pigeon fancying

I like winning and competition, I always have done



Nintendo Wii activities, not a "real experience", I like being in the real world with people, sights and sounds, activities with an atmosphere

Playing pick up football in the park, using our coats as goals, but it doesn't happen any more



Spending time with the children and grandchildren

Do you have any "Magic Moments" to remember?

We went Youth Hostelling, just such fun being with my friends being outdoors


Got lost in this wood, but it didn't matter, just funny getting covered in mud



There was a dance every week, just the highlight for me



What is the best thing about being active?



I like the "experience", shaking hands, having a pint with someone after the game


Clears your mind, takes me away from my dementia for a while

Feeling the sun and wind on my face when I'm outdoors

Just being in the moment, I forget everything else that's going on

It adds structure to my life

What are the biggest challenges you face in taking part?



Understanding my loss of skill and coordination and time I need to learn new skills

Sometimes, using my memory resurrects what I used to be able to do, and was proud of. But forget that I can't do it any more, that's frustrating

Terminology (understanding words) can hold us back

Not sure I would remember any safety instructions or rules

Not knowing how dementia will affect me next or when I may lose a skill

Too much noise I can't deal with it all at once

How can leaders, teachers and coaches provide better opportunities for people living with dementia?



Try to make sure that everyone gets a chance to interact and join in

Quiet spaces to sit out

People talk too fast, the instructions go right over my head

Better welcome, just when I'm feeling really nervous

I need them to understand my memory isn't very good – so they need patience and to give me time when I forget the rules

Must be prepared to explain anything new/changes as many times as required

Use basic exercises/games that are easy to follow and understand

More dementia specific activity groups that use cognitive stimulation and brain challenges that stimulate memory use

I wish they would slow down and give me time, I feel left out when that happens

Doing something "new", often it's too advanced, so I need another way of picking it up

THINK ABOUT ME