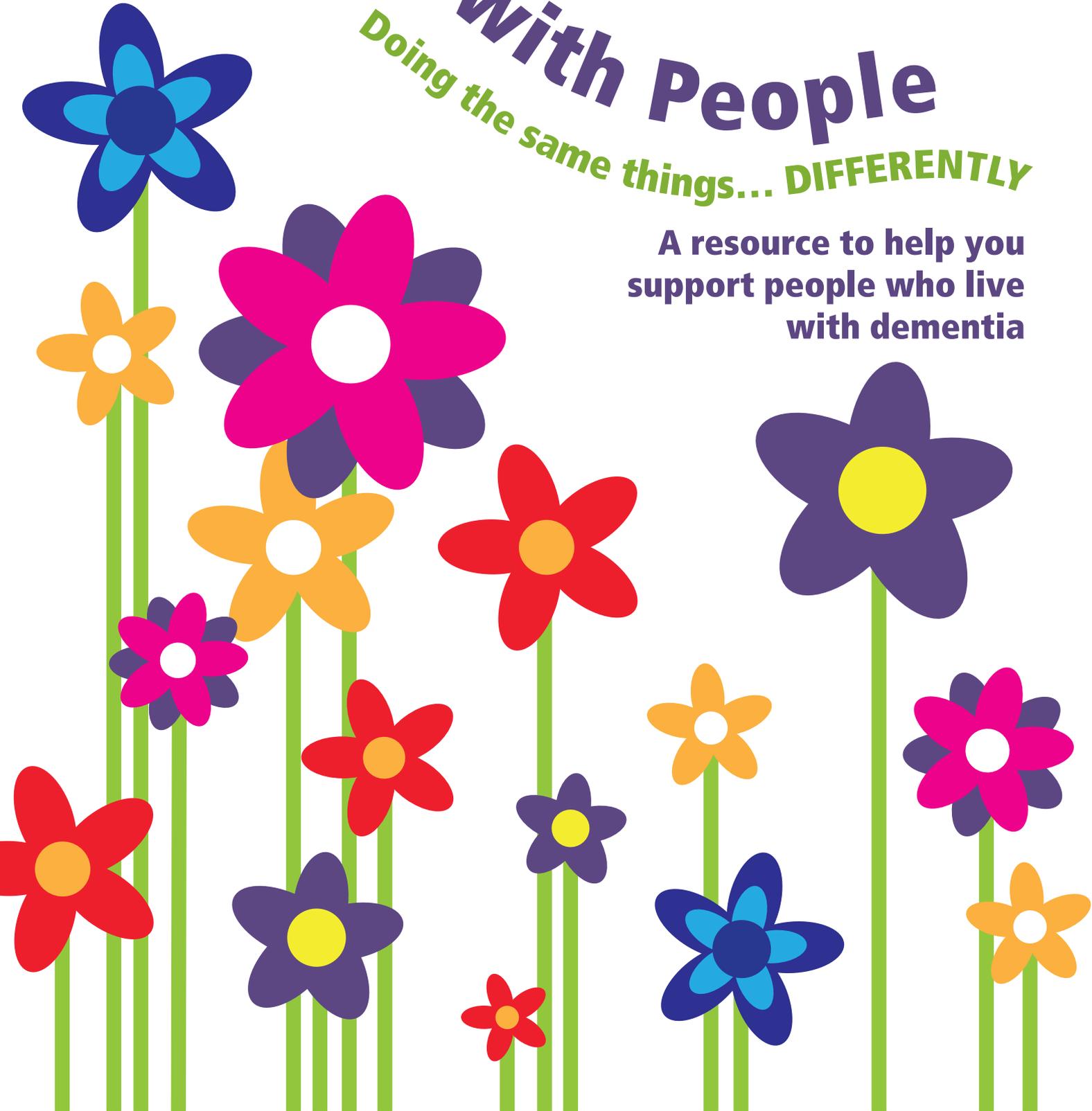




# Connect with People

Doing the same things... **DIFFERENTLY**

A resource to help you  
support people who live  
with dementia





**Hello, I'm Gwen and I live with dementia. Each day can seem a little muddled for me and I forget things very quickly; sometimes I find it hard to tell you what I mean but I love to sing, dance and have fun. I love spending time with people and I am a bit of an actress.**

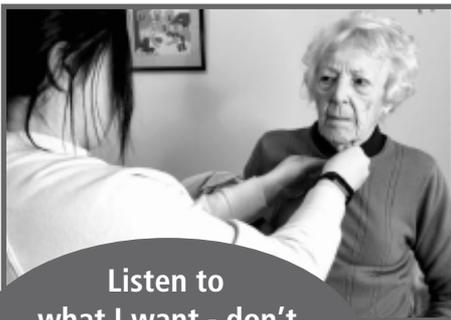
With a little help from my friends I want to try and explain what it's like to be me - my friends tell me how important I am to them and this makes me feel that I belong. You and I can be great friends if we get this right.

So watch my film at [www.reactto.co.uk](http://www.reactto.co.uk) and then we can go through this workbook together.

From my accompanying film...

# LOST

**If you see just my dementia, then you'll lose me. We have made this short film to show how easily this can happen.**

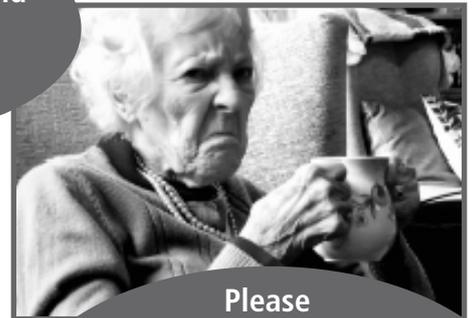


**Listen to what I want - don't fob me off and coax me into something that you want**

**Please go at my pace not yours - don't rush me as it makes me anxious. Sometimes you may need to ignore the words I say but listen to my reactions to get this right.**



**Look at my face and read my eyes - I am LOST**



**Please don't use different mugs, toilets and anything which makes me feel defined by my dementia. I want to experience life alongside you.**

**How did this film make you feel?**

# FOUND

If you remember I am Gwen you will find me and I guarantee you will like what you see!



We really do care about each other.



Use my past to define my present and my future. Remind me who I am and what I am good at. I love acting!



Let's do things together so we matter to each other



Look at my eyes and read how I feel - I am FOUND!

If all you see is my dementia you will miss me in the middle

# DEMENTIA

How did this film make you feel?

In the rest of this workbook we look at ways we can do the same things differently - I promise you it will improve our lives...



*For us living with dementia the danger is not the dementia...  
but the way people without dementia make us feel*

Even though I live with dementia I am the same as you - I have the same feelings and can feel very vulnerable. I may not be able to work things out rationally but I feel things emotionally. The most important thing you can do is make me feel special and valued.

## **Objective**

When we live together it is the little things which become important to me - I love it when you stop to talk to me and involve me in everyday decisions. We can have great fun together.

I see how hard you work and how busy you are. I also see that you have big hearts and I want to thank you for looking after me. If we get this right we can have a ball!

## An Important Bit of History

Tom Kitwood

**Malignant Social Psychology** is the term used by Tom Kitwood to describe the approach to dementia care in the 1990s.

Dementia was seen as a disease and people who had it were sufferers. Treatment was restrictive and institutionalised.

People continued with this as they didn't know any better - it was a harmful and infectious approach.

Tom Kitwood developed person centred care approaches to dementia care between 1989 and 1997. He introduced the idea of **PERSONHOOD**:

*"It is a standing or status that is bestowed upon one human being by others in the context of relationships and social being. It implies recognition, respect and trust."*

We must  
**"hold their story"**  
and respond to them  
**"in the uniqueness  
of their being"**

**Connections**

**Connections are central and this is the focus of this resource**





Tom Kitwood is probably best known for his visual flower representing the six things people living with dementia need to have personhood.

## The Flower of Emotional Needs

### Love

#### Love

Everybody needs to be loved and to love someone; being loved and accepted is part of our need for survival. Love takes many forms - we may love another person, an activity, a hobby or we may have a religious commitment such as loving God. Most importantly we need to learn to love ourselves.

#### Comfort

Feeling comfort is our need to be warm, dry and clean, having a full stomach and not feeling thirsty. Comfort also might mean to have quiet when we want or need it, to be free of pain, to have the freedom to move, and to have a sense of closeness, being able to bond with others.

#### Identity

We all have the need for personal identity; from the clothes we choose to wear, to the food we prefer, and the way we like our hair. These are all identifying factors that help us and others identify with who we are.

#### Occupation

Most of us want to be occupied with something to feel like we have worth and purpose in life. From being involved in daily activities, to engaging in a planned activities programme it's important that the person is able to occupy themselves with meaningful things.

#### Inclusion

Inclusion means that we want to be a part of something. If we feel left out then it makes us feel bad. People living with dementia may lose track of conversation easily; being mindful of their feelings of inclusion is important.

#### Attachment

Our connections in life are also crucial to our feelings of well being. Everyone wants to feel connected to something, or someone; often this is a combination of both. We also have a need to form wider attachments in our community, or in groups.

## What about you?

You and I are no different - we both feel. If you want to understand how I feel then we have to start with you. Fill in the circles below:

**Who is important to you?**

**What things/activities are important to you?**

**How do they make you feel?**

## What about me?

Now do the same exercise but this time imagining how it feels for us when we move into a care home:

**The people we have lost**

**What things/activities have we lost?**

**How does it make us feel?**

**Hold this understanding and carry the potential sense of loss with you as you work!**

# Crossing the Bridge

This represents the experience of dementia and the journey from one reality to another.

If you want to support us, then it is important you recognise where we are on this bridge. You can then adapt your approach so that what you do really helps us.



## Traffic Lights - Understanding Actions!

We all make hundreds of decisions every day about what we do. We go through a process of **FEEL, THINK, ACT:**



Our dementia affects our ability to make rational decisions - the **AMBER light is either not working or flickering (fluctuating capacity).**

So, if I **FEEL** something, I can often no longer **THINK** through any consequences before I **ACT**. This action will appear right to me as it is a way to express my feelings; it may seem inappropriate to you. Please don't judge me.

Look at how I was **feeling** before I **acted** - if you can change this **feeling** to a positive one then my **actions** will reflect this.

## Learning Messages

When you are supporting us remember:

- The way I **ACT** will represent the way I **FEEL**
- Look at why I **FEEL** that way
- My actions appear logical to me - they are a way of expressing my emotions
- Please don't judge me and understand that I am not deliberately trying to upset you by my actions



# The Language of Dementia - Be an Interpreter

We all live in our own reality bubbles - the key is knowing how to join someone else in theirs!

Try joining me in my reality bubble and spend some time with me there. This tells me that you believe me.

**LISTEN & VALIDATE**  
If you tell me I am wrong then I get upset, confused and possibly angry. If you give me time and join me in what I experience then I feel a real kinship with you - this will affect how I ACT.

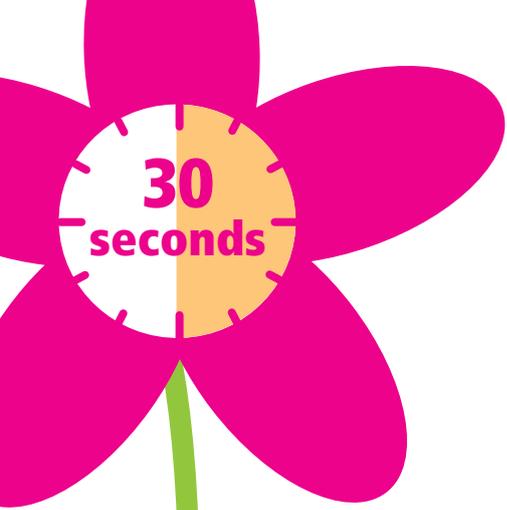


Sometimes I can't find the right words to tell you how I feel so I may use others which are familiar to me and give a voice to my feelings. Please take the time to look at what I am actually trying to tell you.

**Look at Kitwood's Flower and work out what emotion I am looking for when I say these phrases:**

Things you may hear me say	Which part of Kitwood's Flower?	Emotion Expressed
"I have to go now - I'll be late for picking the children up from school"		
"Let me out - I'm locked in a prison!"		
"I really need to get some work done now - I've got to be in a meeting in an hour so let me go"		
"I need to go and see my mum - she's expecting me"		





## Greeting Each Person

When you walk past me without acknowledging me my emotions tell me I don't matter or I may have done something to upset you. These are negative feelings for me and, if I feel like that, it can affect the way I act.

**Just give me 30 seconds in which you make me feel special and valued - honestly, it will change my day!**

**IMPORTANT:** Don't make me feel that it is a 'throw away' unimportant connection - **STOP, MAKE EYE CONTACT WITH ME AND SHARE THE MOMENT.**

On a flip chart record the sort of things you can use. eg share a joke, give a cuddle, tell someone how lovely their hair looks.



A series of 30 second connections may mean that you avoid time managing other situations which arise when people feel they have no identity.



## Don't Talk Over Me!

I can get paranoid when you talk about me as if I'm not there - I feel unimportant and I may assume you are saying bad things about me behind my back.

**Please talk with me - conversations can go through me even if I don't understand what you are saying. This makes me feel included. Keep me in the conversation loop.**

## Occupation

I get really bored when I have nothing to do which makes me feel frustrated. This may come out as anger and you will definitely know how I FEEL through my behaviour.

If you spend time finding out what is important to me you make me feel special. I love to talk about my past and what I have enjoyed - if you make this a reality today I will love it.



**One Page Profile**  
 (Helen Sanderson Associates:  
[www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk))  
 Create a One Page Profile with the person  
 and/or their relatives and use it to shape  
 relevant occupation.

### What is important to me

My family is very important too me. I have 2 sons called Stefan & Chris. I also have 2 grandchildren called Melissa & Daniel

To keep active & busy. I don't like to have nothing to do

I love to get out & about as regular as I can. It keeps me fit & healthy

Music & Dancing.

I really enjoy listening to music & I'll dance along to pretty much anything with a good rhythm

I really enjoy good food & especially my favourite frothy coffee

My time in the WAFF is still very important to me & I still have some great memories. Especially meeting my husband Zygmunt

I love going shopping & I am always on the look out for a good bargain

I enjoy my own space & privacy so please knock before you come in



Gwen

### What those who know me say they like & admire about me

Get Up & Go Attitude

Young at Heart

Fighting Spirit

Kisses & Cuddles

Smiles & Laughter

Sense of Humour

Loves to Dance



### How best to support me

I am very independent in most things but there may be times when I ask for your help

I can get a little confused at times so in these moments please be patient with me & give me a little bit of your time

I love to dance so please feel free to join me when ever you get the chance. Its lots of fun & you might enjoy it

I do most things by myself but I always enjoy a little bit of company with me to maybe explore other things & go a little further

Please be aware that I do have some food allergies & especially things like cheese & chocolate. I have to be careful what I eat at meal times

## Involve Me in Everyday Chores

Everyday stuff is good as that is what I have done all my life and it gives me a purpose. Make me feel part of your family:

- Will you help me with this washing up?
- I could really do with your advice on what to have for tea.
- Let's clear up all this mess - be loads easier if we do it together and you're so good at it.
- I hate odd socks - let's see if we can pair all these up.
- Look at all those leaves - can you give me a hand sweeping up?





## Useful Reading

Brooker, D and Latham, I. (2016). **Person Centred Dementia Care 2<sup>nd</sup> Edition: Making services better with the VIPS framework**. London, Jessica Kingsley Publications

Helen Sanderson. **One Page Profile**.  
[www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)

Kitwood, T (1997). **Dementia Reconsidered: the person comes first**. Buckingham, Open University Press

Kitwood, T. and Brooker, D. (Editor) (2019). **Dementia Reconsidered, Revisited: The person still comes first**. London, Open University Press

Pool J (2011). **The Pool Activity Level (Pal) Instrument for Occupational Profiling: A Practical Resource for Carers of People with Cognitive Impairment**. Jessica Kingsley Publishers

Sheard, D (2007). **Being: An Approach to Life and Dementia**. Alzheimer's Society (first in the series Feelings Matter Most)

**We Are Family - an emotionally led approach**  
[www.youtube.com/watch?v=4gcaElkEFfE](https://www.youtube.com/watch?v=4gcaElkEFfE)

NICE Guideline: **Dementia: assessment, management and support for people living with dementia and their carers**  
[www.nice.org.uk/guidance/ng97](https://www.nice.org.uk/guidance/ng97) June 2018

**My Home Life**  
[www.myhomelife.org.uk/our-guiding-principles/focussing-on-relationships](http://www.myhomelife.org.uk/our-guiding-principles/focussing-on-relationships)

**This resource includes a training film you can view at: [www.reactto.co.uk](http://www.reactto.co.uk)**



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NHS  
England



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Improvement