STEP ONE

Accept the Truth
Session One

• Accepting the truth

• The learning contract

People living with a dementia MATTER

“A person with Alzheimer’s disease is many more things than just their diagnosis. Each person is a whole human being”.

“I’ve been a long way but not here…..This isn’t home, it’s a banjo”.

From “Time to Listen” Sheard et al (2001)
Session One Accepting the truth

Contents

Workshop outline

1  Aims and objectives: Our dementia care philosophy
2  Workshop theme
3  Overall workshop learning
4  Summary of key learning messages
5  Action Plans
6  References and reading list
7  Additional handouts
1. **Aim and objectives**

**Aim**

- To begin the course together as an exciting opportunity to look into the future of dementia care and to explore the worlds – both different and the same - of people living with a dementia.

**Objectives**

- To present the state of the art of dementia care, scene setting the years journey.

- To experience the key themes arising from Dementia Care Matters philosophy.

- To establish this Course requires before commencement a basic understanding of the causes of dementia.

- To ensure that participants understand the nature of the course materials and assignments.

- To create a learning contract between participants and the workshop trainers.

- To be clear that this Course will seek to be person centred towards participants.
‘Feelings Matter Most’
Our dementia care philosophy

Life is an emotional journey

We all crave real human connection. Feelings matter most in all of us. This applies even more to people living with a dementia. Experiencing a dementia eventually involves relying less on facts, logic and reason. When this occurs people living with a dementia are more feeling beings than thinking beings. Feelings will matter even more.

Accepting a person’s reality

All of us live in our own reality. Joining someone in their reality, entering their bubble, is the only way to reach people. Accepting people as they are is the first step in connecting. It is vital to believe that everything a person says and does in life has meaning. This applies even more to understanding people living with a dementia. Trusting there is always a way to reach another person is at the centre of valuing people and life.

Fighting for quality of life in dementia care

Quality of life counts. Everyone needs opportunities to feel alive. This involves care services ‘getting it’. ‘Getting it’ means removing physical and emotional barriers that separate people from one another.

All of us need to feel part of a community. Good quality dementia care looks, sounds and feels like best friends, like a loving family. Quality dementia care is not like a prison, hospital or hotel. It involves everyone living, supporting and working with dementia focusing on quality of life.

Living in the moment

We all live in the moment – moments matter. Staff who ‘get it’ look, sound and feel like butterflies. Being natural in dementia care involves flitting between people, being still, connecting, creating colour and changing moments in people’s lives. For everyone with or without dementia all we have is now. We cannot yet fix dementia as a condition. We can fix our approach.

Showing people living with a dementia that we know their feelings matter most can transform lives.

Being a Star

This philosophy is written by David Sheard, Director: Dementia Care Matters. More detail can be found in his five publications ‘Being’, ‘Enabling’, ‘Inspiring’, ‘Nurturing’ and ‘Growing’ in his Feelings Matter Most series published by Alzheimer’s Society.
2. Workshop theme

Going on a journey: A voyage of discovery

Relevance of theme to the workshop

- **For participants** the course will be a voyage of discovery in learning about people living with a dementia and their experiences.

- This course will also be a journey in learning about how the organisation you work with takes you on this journey towards developing quality care.

- A key part of the journey will be learning more about yourself and the meaning of person centred care to you.

- **For people with dementia** the experiences of dementia are a voyage of discovery, this course will examine how we can make it the most positive journey possible.

- **For the workshop trainer** this will be a voyage of discovery, how best to provide learning and support to staff in their roles at work to improve the experiences of people living with a dementia.
3. Overall workshop learning

At the end of this workshop participants should have gained some understanding that:

- A wide range of feelings are created when going into the unknown on any journey.
- People living with a dementia will experience the journey very individually but feelings will matter most.
- Understanding another person’s journey depends on understanding their uniqueness.
- Each part of our lives has a bearing on others as people with dementia, as colleagues, in our organisation and at home.
- Embarking on a journey can be emotional – fixing dementia care is emotional.
- It is important to look into the future and star gaze at what the future of dementia care could look like and to set off on the beginning of this journey now.

4. Summary of key learning messages

- It is important to understand the feelings people have when going into the unknown including the journey into living with a dementia.
- Everyone with and without the experience of living with a dementia is unique.
- Uniqueness, takes time and trust to discover in each other, this also applies to people living with a dementia.
- We all have feelings about embarking on a journey of discovery.
- Some people living with a dementia may struggle in trying to make sense of the world using their long-term memory.
- It is important for participants to understand the perspective of people living with a dementia.
- A person living with a dementia needs a great deal of reassurance, comfort and support when they appear to fail to make sense of the world.
5. Action plan - Module 1: The Emotional Journey

- **When you return to your care home will you create a workshop programme** in-house - how are you going to create an in-house workshop programme?

- **DVD - Can Gerry Robinson Fix Dementia Care Homes** - How will you ensure that the majority of staff in your care home will watch this and will they then be debriefed on this?

- **Facing the Truth in Dementia Care** - How will you reflect on the truth about quality of life in the care home where you work and share this with your colleagues?

- **DVD – Feelings in Dementia Care Matter** - How many staff will watch this DVD and then debate the difference between being person centred and doing tasks?

- **The 3 Circles exercise** - Doing, Feelings and Spirit. How and when will staff undertake this exercise?

- **The Balloon exercise** - Experiencing dementia, communication and the brain. Will staff undertake this exercise?

- **No More ‘Them and Us’ exercise** - When will the care home begin to look at the removal of barriers within the home between staff and people living with a dementia?

- **Observational audit examples** - positive and negative. When will the staff in the home be given the opportunity to read and listen to the content and discuss parallels within their own care home?

- **Inspiring 50 point checklist** - How as a participant will you share the Yes/No/Partly results with your colleagues?

- **Turning 6 No’s/ Partly’s into 6 Yes’s** - Which 6 from the 50 point checklist will you select and how far will you be progressing on turning the 6 chosen points into Yes’s?
6. References and reading list

Film

Star Trek Video Paramount Pictures.

DVD - FEELINGS in Dementia Care Matter (2011) Dementia Care Matters

DVD – Can Gerry Robinson Fix Dementia Care Homes? Open University

Music

Holst G The Planets ISBN: B000003CU0

Books


Reading List


Killick, J (1997) You are words Hawker Publications London


Murphy, Charles J (1995). It started with a seashell: Life story work and people with dementia. Dementia Services Development Centre, University Of Stirling. www.stir.ac.uk/dsdc


7. Additional handouts are on the following pages
Culture Change in Dementia Care course information sheet

What will I be doing on the course?

This course provides participants with 13 full day workshops. These workshops will provide participants with information given in different ways, sometimes as presentations, group or individual exercises and video extracts.

- What will be expected of me?

The course material will provide participants with an opportunity to reflect on what they have seen or heard during the workshops. Participants are also expected to use their experience of working with people living with a dementia in their learning and to carry the learning into the workplace at the end of each workshop by completing a short action plan which will be followed up at the beginning of the next workshop.

- What is experiential learning?

People learn from their experiences and the results of that learning can be used constructively in your assignments and at work.

However it is not sufficient to have an experience in order to learn. Without reflecting on the experience, discussing it with others and in the workshops the potential learning cannot be fully explored.

- How much time will the course take?

There are twelve workshop sessions, in addition to that participants are asked to complete three assignments, one each term. In order to get the most out of the course participants are expected to read books and journals from the reading lists given at the back of the manual listed module by module. Participants should be prepared to spend one and a half to two hours a week on reading and course work.

- What are the assignments?

These are three pieces of written work that demonstrate your ability to put the theory you have learnt into practice at the workplace. Guidelines for assignments and the marking criteria are in the manual.

- What happens if I do not pass an assignment?

You will be given an opportunity to re-write the assignment.
• **What do I get at the end of the course?**

Participants who have passed their assignments will be awarded the Culture Change in Dementia Care Course by Dementia Care Matters on the last day of the course and will be eligible to apply for 30 level 6 credits towards a BSc in Professional Practice (Dementia Care) at the University of Surrey – these are transferable to other courses.

For those who chose not to do assignments a certificate of attendance will be awarded.

If you have any other questions about the course and the expectations of participants please do not hesitate to ask any of the workshop trainers. We all hope you enjoy it.
BEING v DOING

MYSELF

WHAT I DO IN LIFE

THE FEELINGS I HAVE CURRENTLY IN MY LIFE

THE CORE OF ME – SPIRIT

FEELING

DOING
BEING v DOING

SOMEONE I SUPPORT EXPERIENCING A DEMENTIA

WHAT THEY DO IN THEIR LIFE

THE FEELINGS THEY HAVE CURRENTLY IN THEIR LIFE

THEIR CORE – SPIRIT

FEELING

DOING