Northumberland, Tyne and Wear NHS

NHS Foundation Trust

Lie therapy: person centred communication

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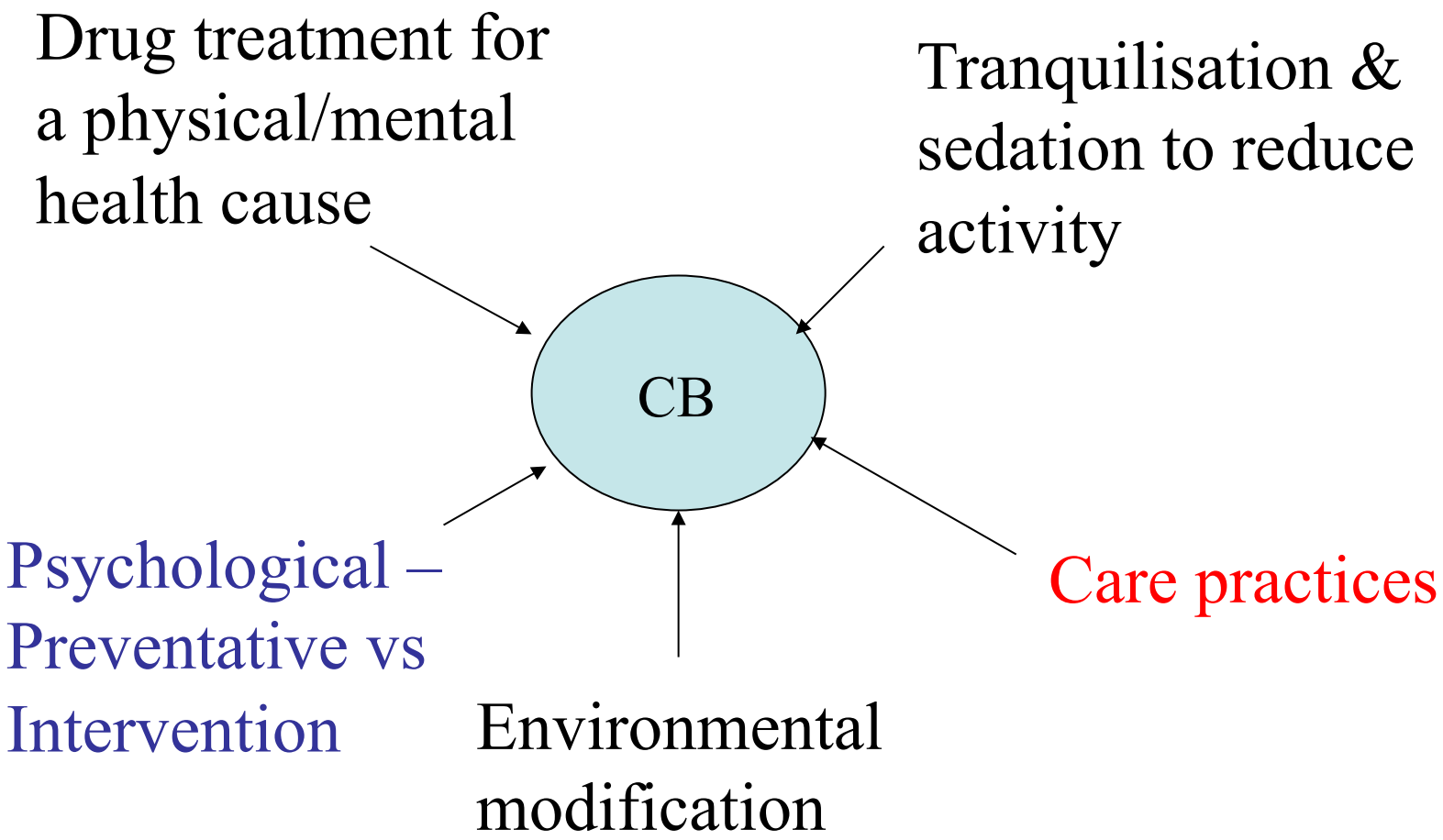
Treatment strategies



National guidelines

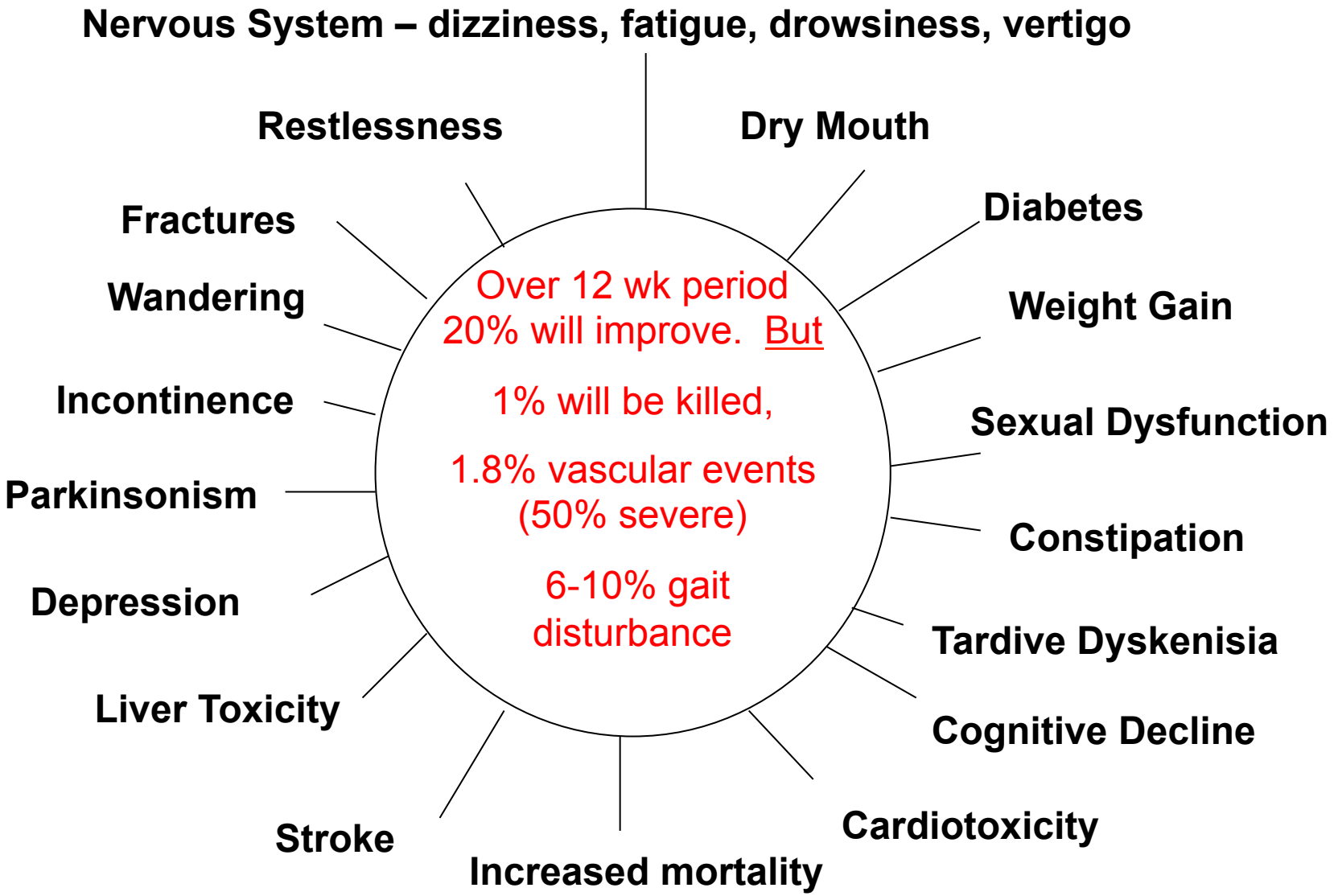
- Functional analysis (behaviour)
- Reminiscence, life review
- Validation therapy
- Reality orientation
- Cognitive Stimulation therapy
- Music
- Aromatherapy
- Multi-sensory
- DCM

Aims of Team

- Carer-centred, person-focused interventions
- Biopsychosocial model (drugs)
- Treat in the current setting
- Work collaboratively, with resources available
- Prevent unnecessary admissions
- Facilitate effective discharges and transfers.

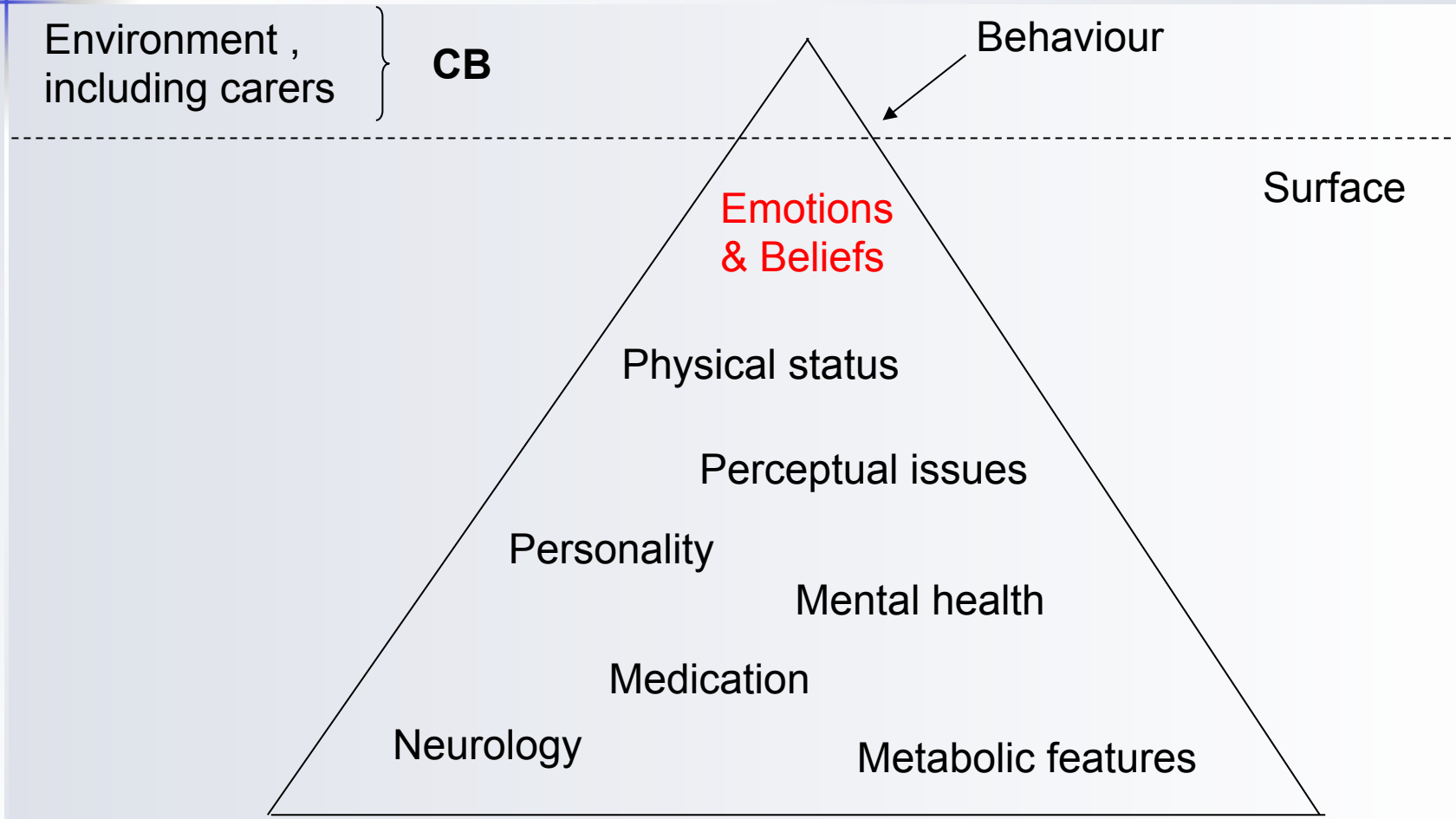
List of common behaviours that challenge

Aggressive forms of CBs	Non-aggressive forms of CBs
Hitting	Repetitive noise
Kicking	Repetitive questions
Grabbing	Making strange noises
Pushing	Constant requests for help
Nipping	Eating/drinking excessively
Scratching	Over-activity
Biting	Pacing
Spitting	General agitation
Choking	Following others/Trailing
Hair pulling	Inappropriate exposure of parts of body
Tripping	Masturbating in public areas
Throwing objects	Urinating in inappropriate places
Stick Prodding	Smearing
Stabbing	Handling things inappropriately
Swearing	Dismantling objects
Screaming	Hoarding things
Shouting	Hiding items
Physical sexual assault	Falling intentionally
Verbal sexual advances	Eating inappropriate substances
Acts of self harm	Non-compliance

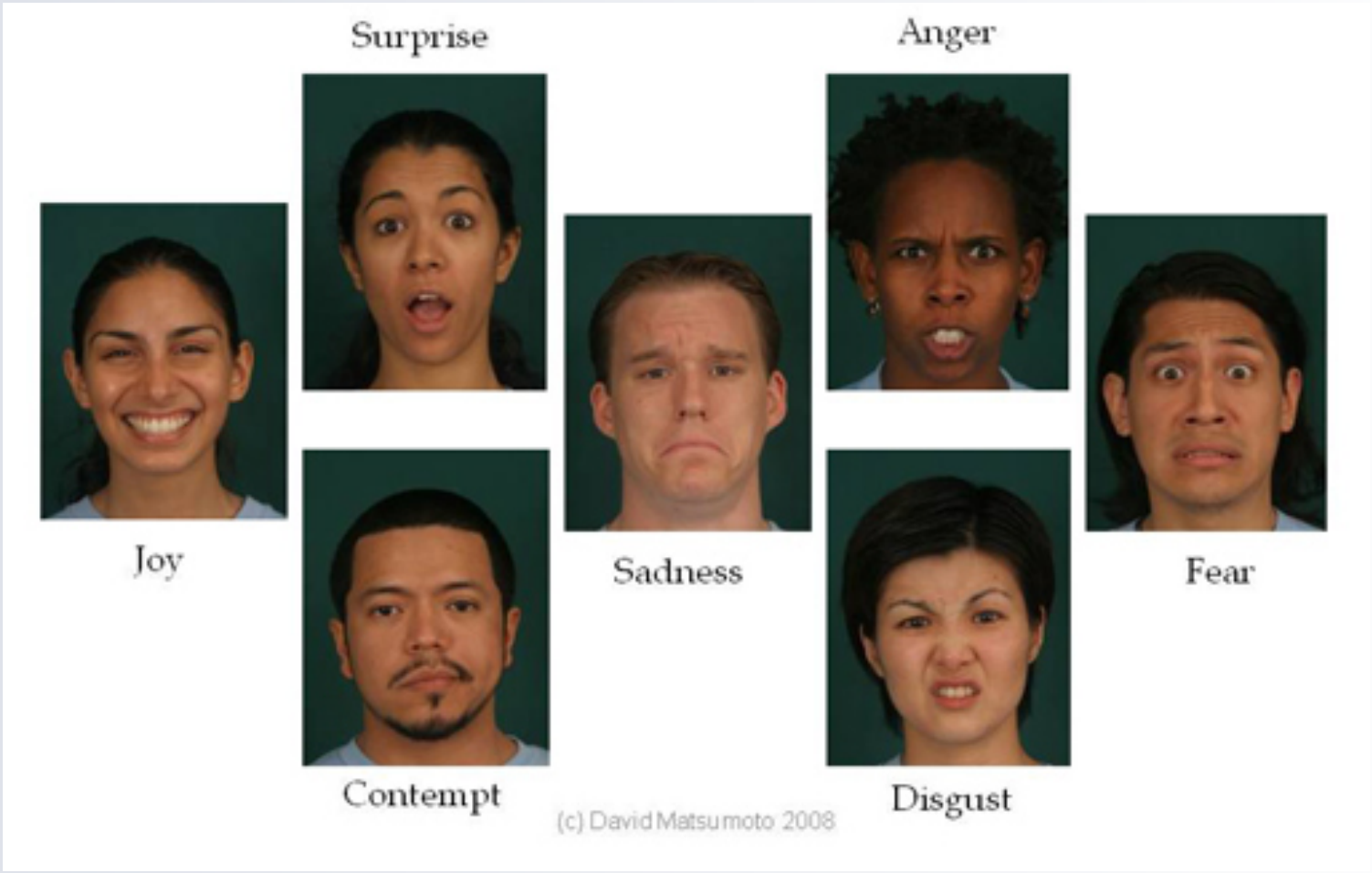


Anti-psychotic side-effects (Banerjee, 2009)

Figure 1: Iceberg Analogy



Seven basic emotions



Themes associated with emotions

- Depression (worthless, negative, hopeless)
- Anger (rights have been infringed, protect self-esteem)
- Fear (vulnerable, chaotic, unpredictable)
- Shame (major intrinsic fault others are aware of)
- Disgust (contaminating stimuli forced to face)
- Contempt (judge others as being worthless or their actions)

- Happiness
- Complex emotions - pride

Aim

Avoid PWD

- People feeling undervalued, vulnerable, their rights infringed, loss of dignity, sense of shame & hopeless.
- Living in an environment that is poor, chaotic, hostile and disgusting, with few positive routines, occupied by people who unable to relate to or who feel are not worth engaging with.

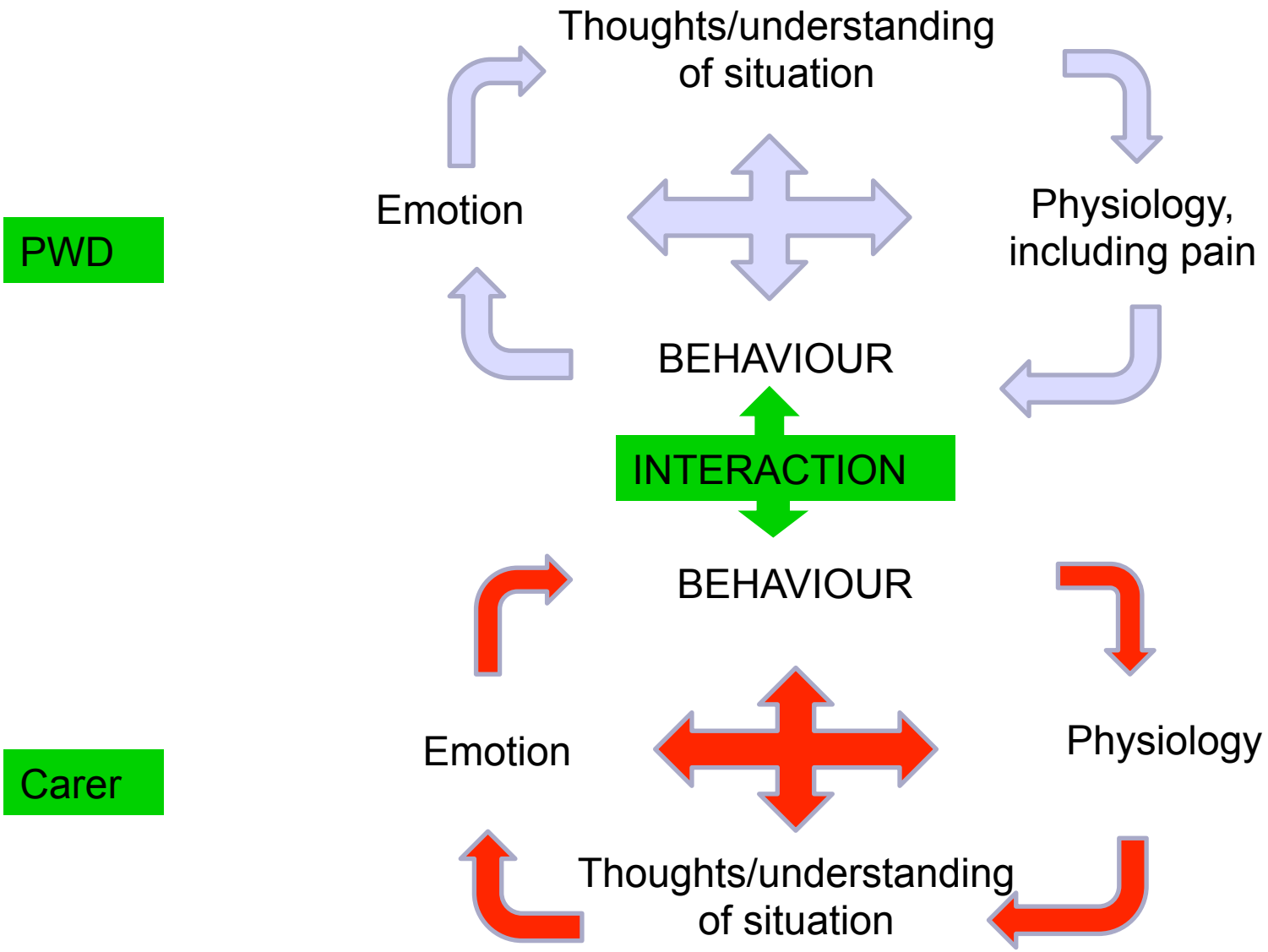
- Happiness, contentment, & reverse of above

Communication

Non-pharmacological interventions - Quality Interactions

Interactions

- STOP
- START
- MacModel


PWD
Thoughts/understanding of situation
Emotion
Physiology, including pain
BEHAVIOUR
INTERACTION
BEHAVIOUR
Carer
Emotion
Physiology
Thoughts/understanding of situation

PWD

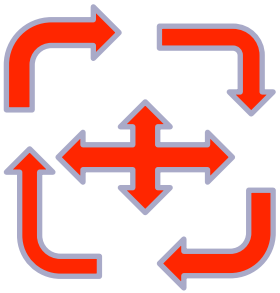
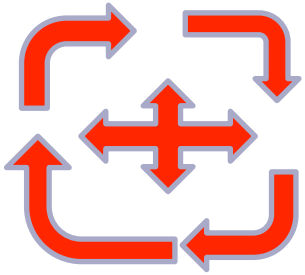
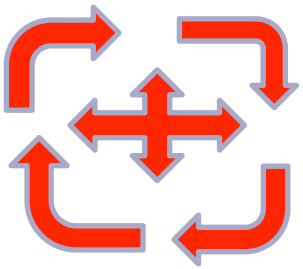
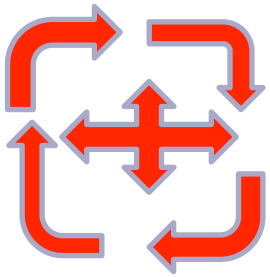
Thoughts/understanding of situation

Emotion

Physiology, including pain

BEHAVIOUR

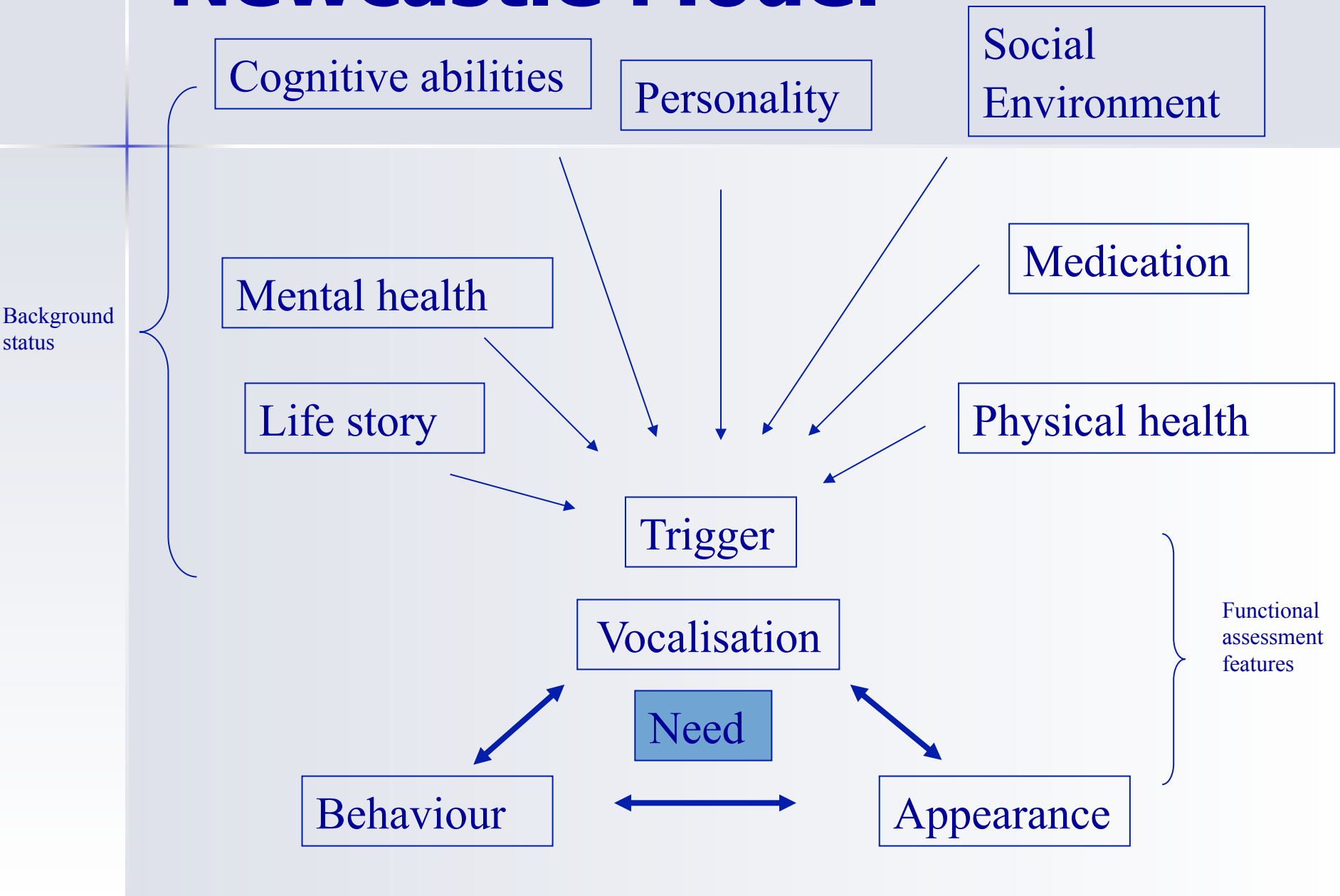
INTERACTION

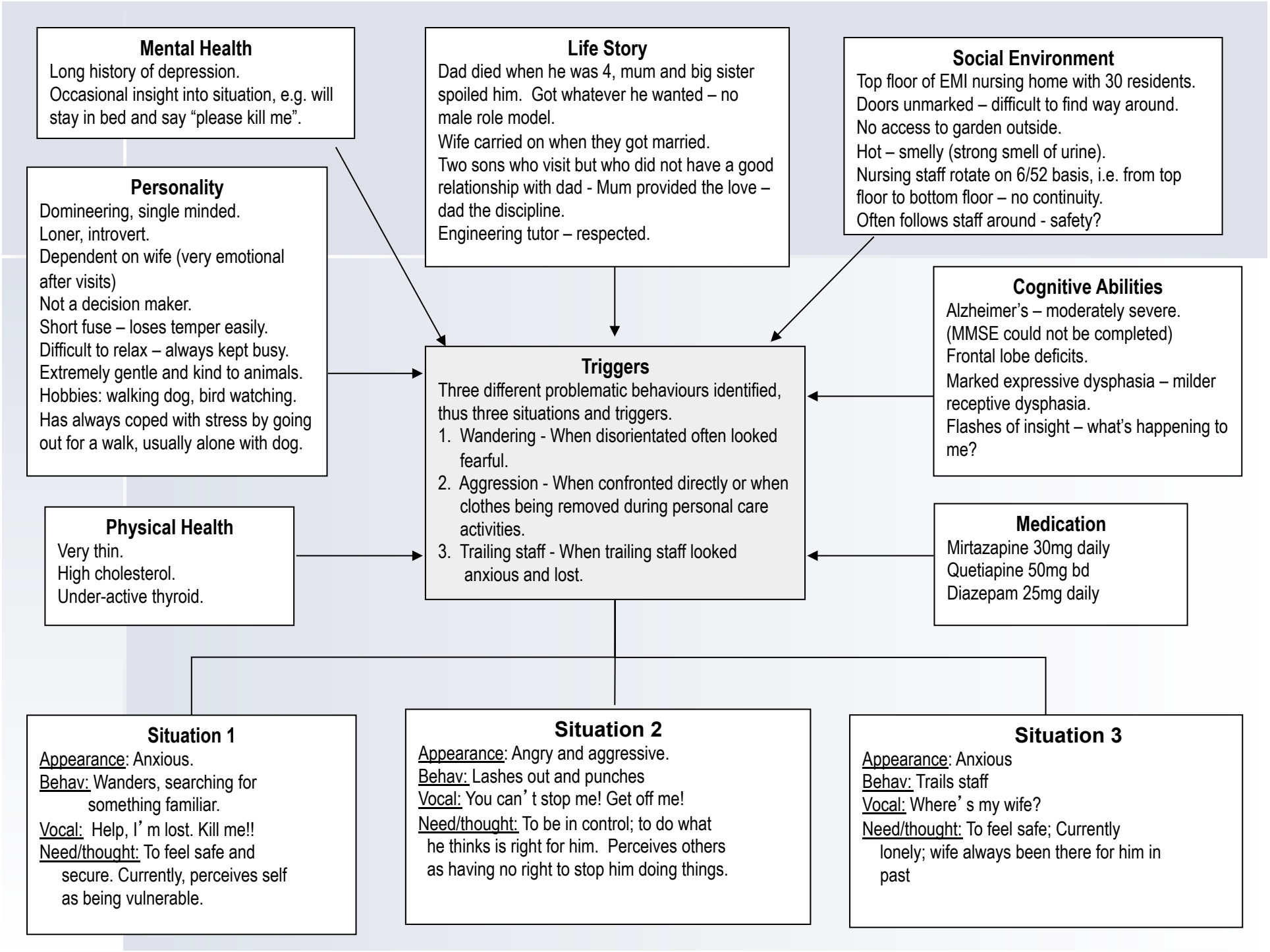





WH framework

- What want to deliver
  - Quality interaction with person with dementia – evidence based approaches, individualised communication (theory of mind)
- How to deliver (philosophy)
  - Why – rationale their role as the agent of change
  - When – consistency and routine

Newcastle Model




Mental Health
Long history of depression.
Occasional insight into situation, e.g. will stay in bed and say "please kill me".
Life Story
Dad died when he was 4, mum and big sister spoiled him. Got whatever he wanted – no male role model.
Wife carried on when they got married.
Two sons who visit but who did not have a good relationship with dad - Mum provided the love – dad the discipline.
Engineering tutor – respected.
Social Environment
Top floor of EMI nursing home with 30 residents.
Doors unmarked – difficult to find way around.
No access to garden outside.
Hot – smelly (strong smell of urine).
Nursing staff rotate on 6/52 basis, i.e. from top floor to bottom floor – no continuity.
Often follows staff around - safety?
Personality
Domineering, single minded.
Loner, introvert.
Dependent on wife (very emotional after visits)
Not a decision maker.
Short fuse – loses temper easily.
Difficult to relax – always kept busy.
Extremely gentle and kind to animals.
Hobbies: walking dog, bird watching.
Has always coped with stress by going out for a walk, usually alone with dog.
Triggers
Three different problematic behaviours identified, thus three situations and triggers.
1. Wandering - When disorientated often looked fearful.
2. Aggression - When confronted directly or when clothes being removed during personal care activities.
3. Trailing staff - When trailing staff looked anxious and lost.
Cognitive Abilities
Alzheimer's – moderately severe. (MMSE could not be completed)
Frontal lobe deficits.
Marked expressive dysphasia – milder receptive dysphasia.
Flashes of insight – what's happening to me?
Physical Health
Very thin.
High cholesterol.
Under-active thyroid.
Medication
Mirtazapine 30mg daily
Quetiapine 50mg bd
Diazepam 25mg daily
Situation 1
Appearance: Anxious.
Behav: Wanders, searching for something familiar.
Vocal: Help, I'm lost. Kill me!!
Need/thought: To feel safe and secure. Currently, perceives self as being vulnerable.
Situation 2
Appearance: Angry and aggressive.
Behav: Lashes out and punches
Vocal: You can't stop me! Get off me!
Need/thought: To be in control; to do what he thinks is right for him. Perceives others as having no right to stop him doing things.
Situation 3
Appearance: Anxious
Behav: Trails staff
Vocal: Where's my wife?
Need/thought: To feel safe; Currently lonely; wife always been there for him in past

6 plus 6 week format

WK 1-6 intensive

- Ensure physical checks have been done
- Formulation

WKs 7+

Follow-up and tweaking

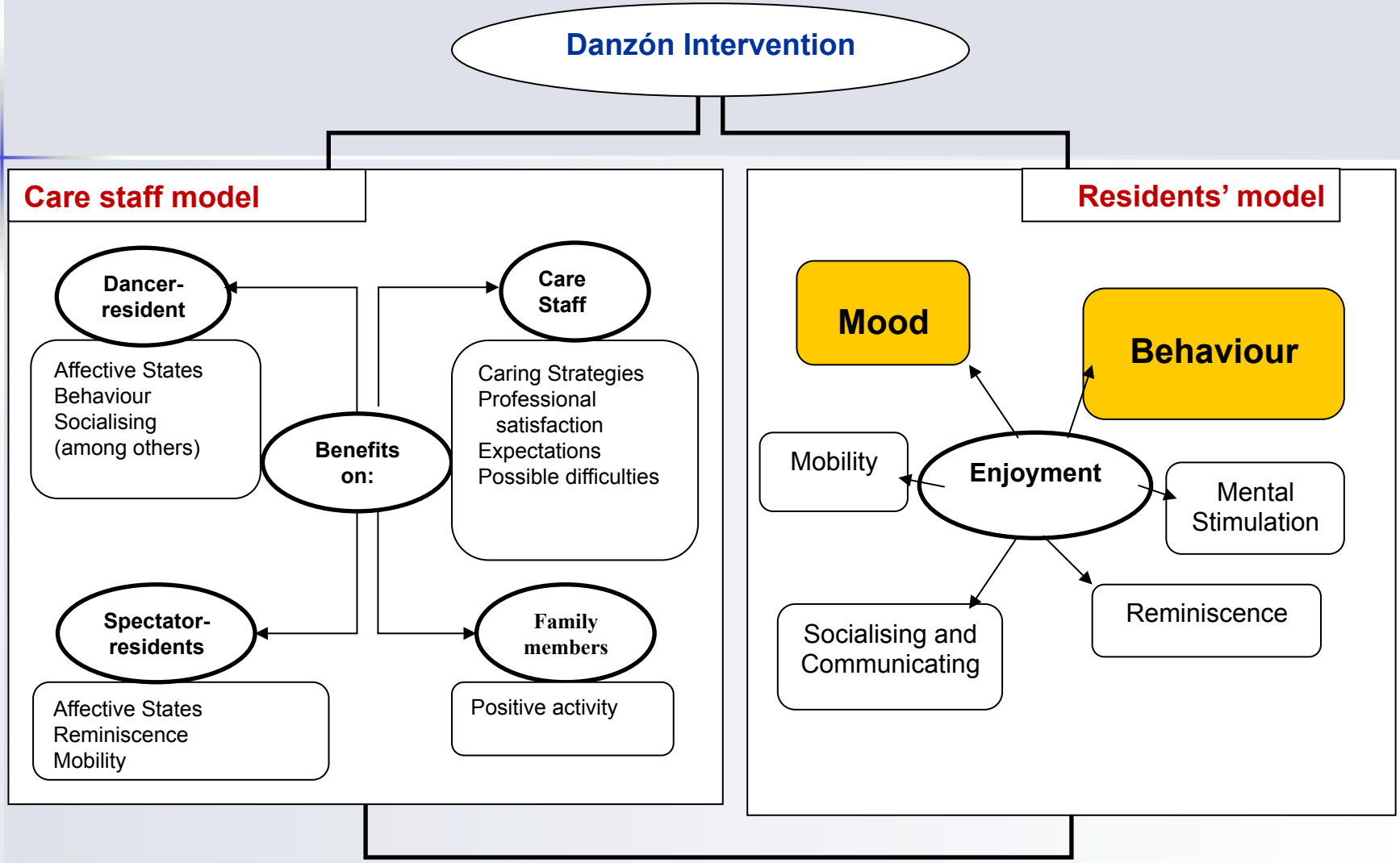
LCAPS

- Listen
- Clarify
- Agree
- Plan
- Support

• Improve communication	• 67
• Provide personalised activity	• 39
• Consistent approach from staff	• 37
• Change in physical interpersonal interactions with client	• 28
• One-to-one time	• 15
• Promote independence	• 15
• Offer client choice (for example (clothing or activity)	• 12
• Provide explanation of action	• 10
• Ensure client is alert prior to commencing interventions	• 8
• Empathise	• 7
• Gain permission to enter personal space	• 7

Therapies – Programmatic research (unfunded)

- Dance
- Spiritual
- Doll therapy
- Therapeutic use of lies/deceptions
- Music
- Simulation presence
- Toilet therapy



Guzmán-García, James, Mukaetova-Ladinska (2012) 'Dementia'

Why is doll therapy effective?

Therapeutic lies

- Entering the belief system of the PWD and responding appropriately to his/ her world

Who?

Four studies

- Survey (James et al, 2006 – In J. Geriatric Psych.)
- Staff's perceptions (Wood-Mitchell al, 2007, J. Dementia Care)
- Changing perceptions/development of a questionnaire – Coronation street study (Elvish et al. 2010 - Ageing Mental Health)
- People with dementias' perceptions (Day et al. 2011 Ageing and Mental Health)

Publications in PSIGE Newsletter, Journal of Dementia Care

What constitutes a lie?

- Different types of lies (Vrij, 2000)
  - Subtle lying: Literal truths aimed to mislead, or concealment of the truth
  - Outright lying: incorrect information given intentionally which is different to the facts

"I need to go home to collect the kids from school."

"I need to know that my husband is all right. He's not been well?"

Blum's Categories - Nature of deception

1. Going Along: Not challenging ideas that are factually incorrect in everyday reality or hallucinations. May involve omitting the truth

A person with dementia asks to see her deceased mother. The carer responds, 'she is not here right now'.

2. Not Telling: Keeping impending events from a person with dementia. It is a preventive action on the part of the carer. An omission of the truth.

Not telling a person with dementia that they have an appointment with the doctor until they are due to leave.

3. Little White Lies: An untrue verbal statement.

A woman with dementia is refusing to get up. A carer tells her that her daughter is going to visit later.

4. Tricks: An action on the part of the carer that relies on a lack of reasoning ability on the part of the person with dementia.

A person with dementia insists on always wearing the same trousers (even at night). Following a bath, a carer removes the trousers and claims that she cannot find them

Previous research

- Hasselkus (1997) used in a variety of responses to maintain patients' safety, including deception
- Blum (1994) deception is 'widespread' among family caregivers as the person becomes more disorientated and difficult to reason with
- Kitwood (1997) critical of an 'Alzheimer culture' - deceptive practices are widely taken for granted

  - malignant social psychology

Study 1

- Aims of the study
- Methodology
- Results - lies told
  - frequency
  - other factors
  - qualitative data
- Discussion of findings, application of findings, ethical implications

Aims of study

- Explore issue of lying within dementia care settings (building upon pilot)
- Investigate prevalence of lies within care settings
- Reasons why people lie to people in care
- Other factors influencing 'lie-telling'
- Potential problems of lying
- Guidelines for lie telling
- ✓ Bring the issue into the open.

Methodology

Participants

- 112 participants (64 NE England, 58 S.Ireland)
- Various care settings- residential homes, EMI, hospital wards
- Care staff, psychologists, RMNs, RGNs, Consultants, Doctors, Managers, OT's, RPNs

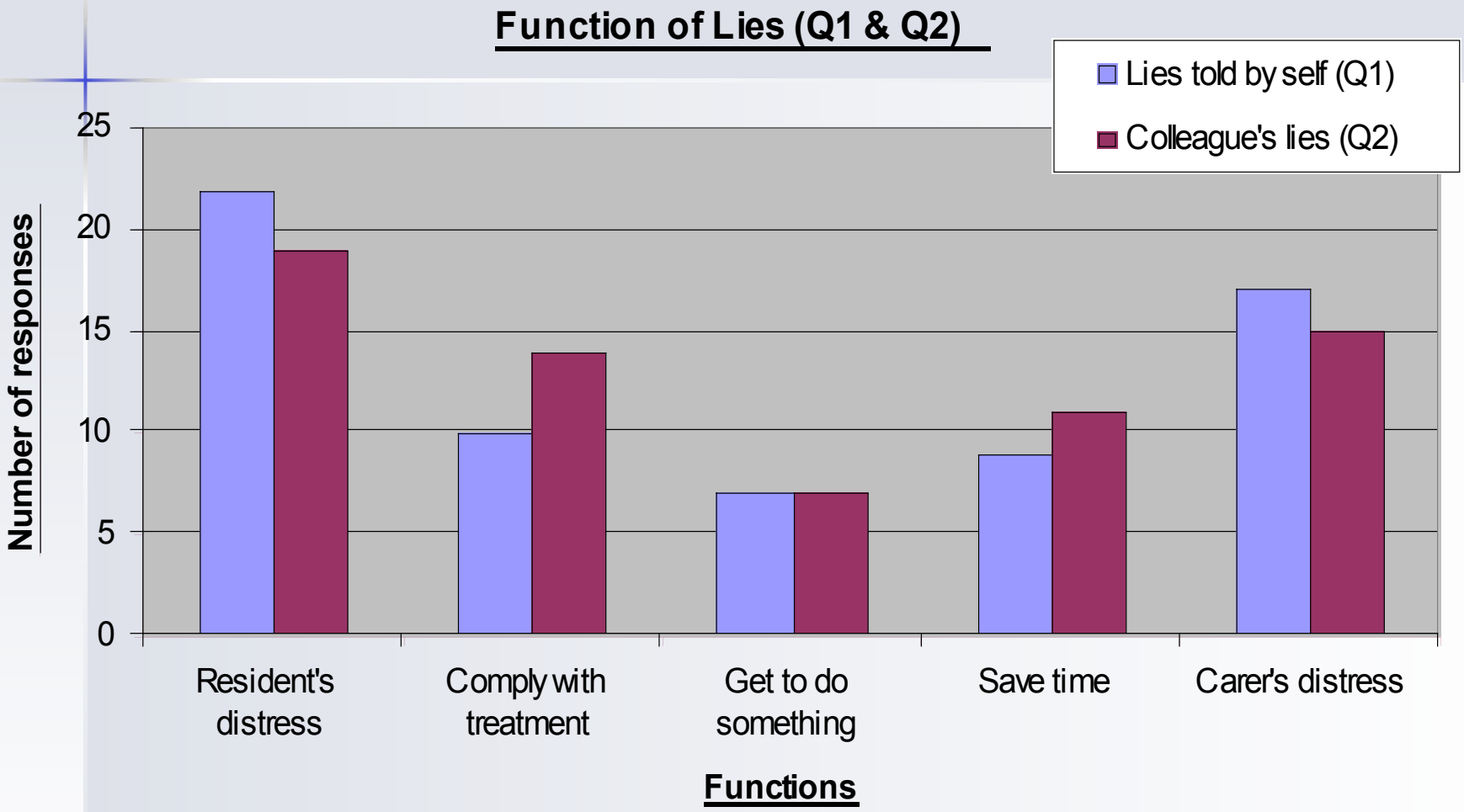
Methodology

Items

1. Frequency of lies told by self, reasons
2. Frequency of colleague lies, reasons
3. Considerations more/less likely for lie to be told
4. Line manager
5. Beneficial lies
6. Guidelines/policies

Results

- 4 of the 112 participants stated did not lie.
- Of these 4, 2 noted that their colleagues did.
- It is therefore evident that lying is pervasive across all type of homes and professional groupings.


Function of Lies (Q1 & Q2)
Lies told by self (Q1)
Colleague's lies (Q2)
Number of responses
25
20
15
10
5
0
Resident's distress
Comply with treatment
Get to do something
Save time
Carer's distress
Functions

Results

- Factors influencing the telling of lies

- The resident would become distressed if told the truth

- The resident would become aggressive if told the truth

Results- nature and consequences

- 93% thought lying could be beneficial:

- reduce concern when asking about deceased loved ones
- when looking for family
- improve compliance with care needs
- reduce desire to leave
- improve medication compliance

- "*Your husband has gone fishing and will be back later*"
- "*Here's the chiropodist you agreed to see* - she'd not actually agreed to see the chiropodist"

Results- nature and consequences

- 88% acknowledged there could be problems associated with lying in this context:

- increase confusion due to lack of consistency
- increase residents' distress
- cause friction between parties
- cause distrust
- recognised as a lie by some residents
- problematic for carers

- *"If the lie is remembered and proves false, this can cause major problems…"*
- *"Not everybody is telling the client the same lie"*

Policies and procedures

- 81% of participants felt comfortable in telling their manager that they had lied
- 85% stated they would welcome guidelines on lying
- 52% offered suggestions as to the content of guidelines on lying

Coronation Street – Study 2/3

- Data from Grounded theory project
- Questionnaire
- Video of Mike Baldwin
- Debate

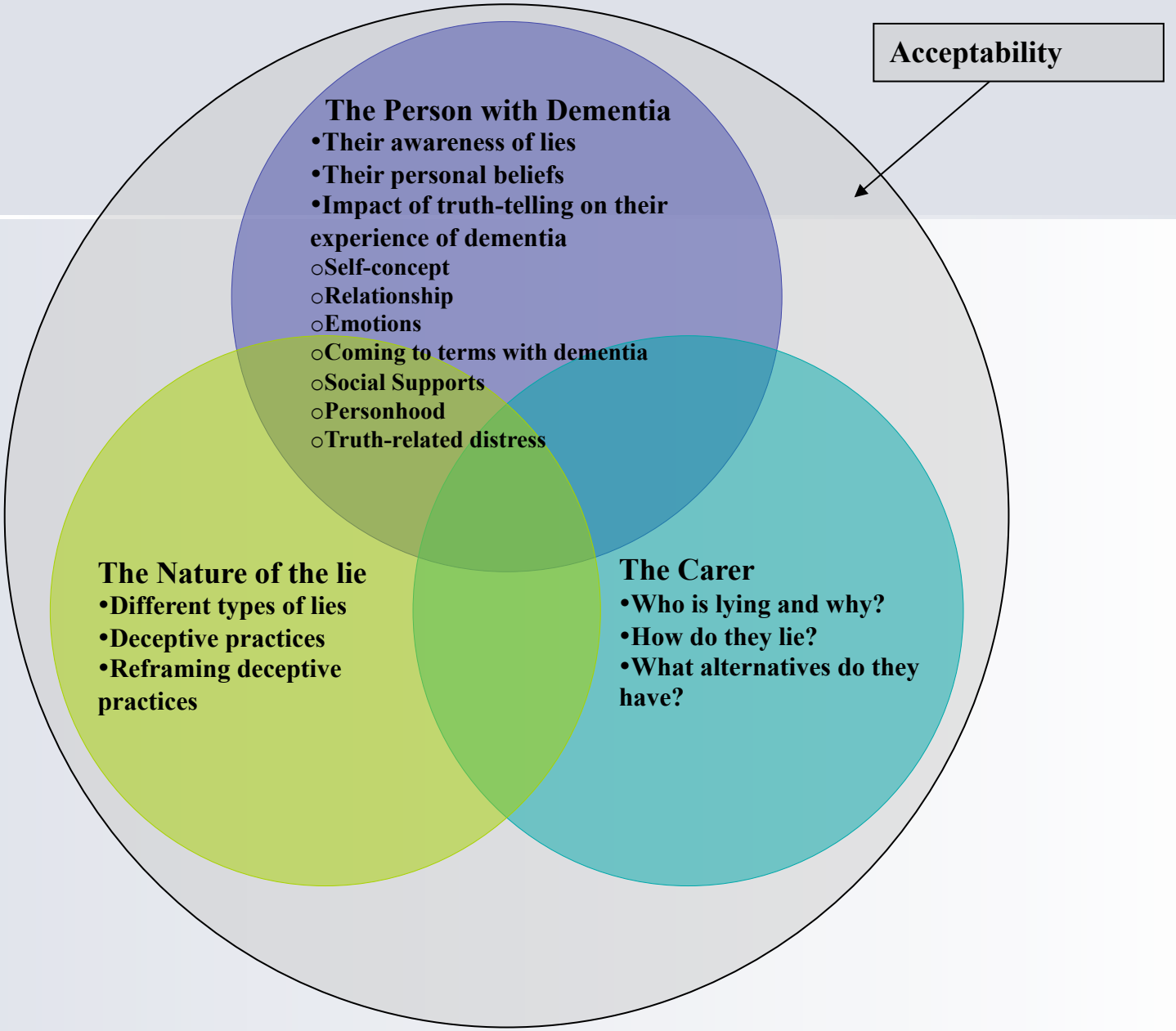
- Pre/post administration of a questionnaire

Coronation Street Video

Self Perceptions – Study 4

- Qualitative, grounded theory study

- Focus group (N=4)
- Interview (N=8)


Acceptability
The Person with Dementia
•Their awareness of lies
•Their personal beliefs
•Impact of truth-telling on their experience of dementia
○Self-concept
○Relationship
○Emotions
○Coming to terms with dementia
○Social Supports
○Personhood
○Truth-related distress
The Nature of the lie
•Different types of lies
•Deceptive practices
•Reframing deceptive practices
The Carer
•Who is lying and why?
•How do they lie?
•What alternatives do they have?

The Person with Dementia

- **Their awareness of lies**
- **Their personal beliefs**
- **Impact of truth-telling on their experience of dementia**
  - **Self-concept**
  - **Relationship**
  - **Emotions**
  - **Coming to terms with dementia**
  - **Social Supports**
  - **Personhood**
  - **Truth-related distress**

The Person with Dementia

- Their awareness of lies

  "It would make them more upset, when they realise it's a lie." (Abigail)

- The impact of the lie on people's experiences of dementia
  - Negative
    - E.g. Relationships, self concept
  - Positive
    - Reduces truth-related distress

- Personal beliefs

  "The truth, the truth, you cannot beat the truth, 'cause it comes out somewhere, sometime." (Theresa)

  "It's human to lie. Why should we be treated differently."

The Nature of the lie

- Different types of lies
- Deceptive practices
- Reframing deceptive practices

The Nature of the Lie

- Different types of lies (white lies, bending the truth, economical, out-right)
- Deceptive practices (hiding things, covering things up, painting doors, removing handles)
- Reframing deceptive practices – whose interests? Be up-front! Own up to them and don't hide behind them.

The Carer

- Who is lying and why?
- How do they lie?
- What alternatives do they have?

The Carer

- Who is lying and why?
  - Most participants were more upset by the thought of a relative or close friend lying

    ***"I wouldn't like a family member lying to us…because we have never ever done that, we have never lied to each other."* (Theresa)**

- How do they lie (intentionality)?
  - Maintain personhood
  - Individually (*Husband has gone to shops!!!!)*

Reflection on results

Need for Guidelines

When to lie? (DVD)

Truth should be trialled as the first approach, before lies

- **Stage 1** – Identify person's need & attempt to **meet the need** directly (Wants to see son, ask son to visit).

- **Stage 2** – Attempt to **simulate/substitute the need** (Simulation presence or If person wants to see her deceased mother, hypothesise that the underlying need may be able feeling insecure.

- **Stage 3** – **Distract** the person if possible, moving their focus to some other thing or person (If current focus is 'wanting mother', can we shift mental focus onto helping set the table for meal time).

- **Stage 4** –**therapeutic lie.**

12 Guidelines (Mackenzie et al, 2004)

1. A clear definition of what constitutes a 'lie' should be agreed.

2. In the 'best interest' of the resident e.g. to ease distress.

3. Care planning.

4. Consideration should be given to cognitive capacity, such as a residents' ability to retain the truth.

Guidelines cont.

5. Communication with family and consent.

6. Once a lie has been agreed it must be used consistently.

7. Lies told should be documented.

8. An individualised and flexible approach should be adopted towards each case – the relative costs and benefits.

Guidelines cont.

9. Staff should feel supported by manager and family.

10. Circumstances in which a lie should *not* be told should be outlined and documented.

11. The act of telling lies should not lead staff to disrespect the residents.

12. Staff should receive training.