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Living well with dementia

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Learning Disabilities Services

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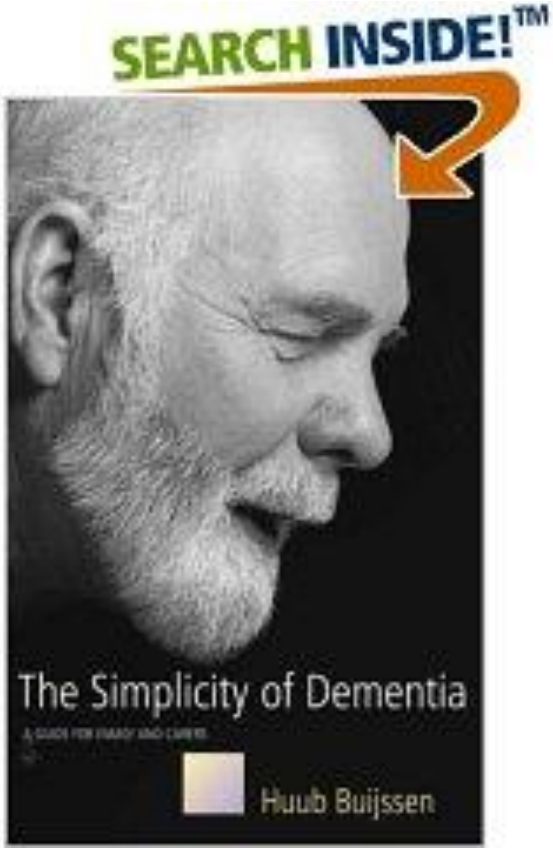
What I have been asked to explore with you

- Models of understanding dementia in LD
- Adjusting support to meet people's needs
- Outcome measures – Dementia in LD


SEARCH INSIDE!™
The Simplicity of Dementia
Huub Buijssen

The law of disturbed encoding

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- The person is no longer able to successfully transfer information from their short term memory and store it in their long term memory. This basically means that the person is unlikely to remember things that have just happened to them.

- The main consequence of disturbed encoding is that the person is unable to form any new memories for the things they experience or for things they are told.

Consequences of disturbed encoding

- Disorientation in an unfamiliar environment
- Disorientation in time
- The same questions are asked repeatedly
- The person quickly loses track of conversation
- The person is less able to learn anything new
- The person easily loses things
- The person is unable to recall people they recently met
- Appointments are quickly forgotten
- People experience anxiety and stress

The law of roll-back memory

- Long-term memory contains all the memories that have been acquired from most recent memories working back toward childhood memories.
- When you develop dementia you will be unable to form any new memories after this time.
- At first long term memories will remain intact, however as dementia progresses, long term memories will also begin to deteriorate and eventually disappear altogether.
- Deterioration begins with the most recent memories and progresses until only memories of early childhood remain, hence memory can be said to be ‘rolling back’.

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Consequences of roll-back memory

- Loss of daily skills such as using kitchen appliances
- Memory loss for events beginning with the most recent
- Decreased social skills and inappropriate behavior
- Decreased vocabulary and inability to find words.
- Disorientation towards people: inability to recognise family and relatives
- The person may begin to have ‘flashbacks’ and see people from their past
- Self care skills will begin to deteriorate
- Changes in personality
- Person believes that they are younger and that time has actually ‘rolled back’





Social model of dementia

- Proposes that people have an impairment, but are disabled by the way they are treated by or excluded from society.

Advantages of this framework are that carers and staff will understand that dementia is:

- not the fault of the individual
- the focus is on the remaining skills rather than losses
- the individual can be fully understood (their history, likes / dislikes etc)
- the influence of an enabling or supportive environment
- the key value of appropriate communication
- opportunities for stress-free and failure-free activities

What does this mean in practice?

- This means that the responsibility to continue to reach out to people with dementia lies with people who do not have dementia.

- Carers and staff need to change their approach to ‘go with’ the person and their continuing changes.

What is the challenge?

90% of Catastrophic Behaviours in people with Dementia are induced by Carers and the Environment.

Brawley E (1997) Designing for Alzheimer's Disease. Strategies for creating better care environments.

Establish a philosophy of care

Excellence in dementia care requires staff and family carers to:

- understand and know the person
- understand dementia and its consequences for the person
- and to consequently be able to think ahead and predict ‘stressors’.

- They need to adapt their approach to ensure that the person with dementia has:
  - **stress free**
  - **failure free**
  - **individualised care**
  - **that is consistent**
  - **without time pressures**.
- needs to be incorporated into the person's person centred plan.
- can only be achieved by having a thorough knowledge and understanding of the person and their history. This can be aided by the ongoing use of Life Story work.
- Need to maintain all the elements of normal daily living to retain skills for as long as possible.
- Need to adapt support as the dementia progresses

Be clear about what needs to be achieved

- not the time for learning new skills, achieving goals or facing change.
- consider the person's happiness, comfort, and security.
- the focus of care should move away from targets to quality of life.
- People compensate for their deterioration in functioning by making greater use of remaining abilities e.g. earlier memories.
- Roll back memory may also mean that the person is not oriented to the present day. Care needs to be taken not to routinely challenge the person's beliefs as this will add to their stress.
- Need an increasing awareness of the physical consequences of getting older and additionally having dementia.
- Ensure that diagnostic overshadowing does not occur
- Pain recognition and management is often extremely inadequate

How can we support people?

After implementing the philosophy of care, other approaches include:

- Physical environment
- Activities and Intervention
- Anxiety and stress reduction
- Life story work
- Reminiscence
- Reality orientation
- Validation
- Understanding behaviours

Importance of environments

- Environments play a huge role in the wellbeing of people with dementia
- Dementia enabled environments can prevent and reduce behaviour
- Changes needn't cost a lot but make a huge difference

Environments may need to be altered to be:

- **Calm**
- **Predictable and making sense**
- **Familiar**
- **Suitably stimulating**
- **Safe and risk assessed**

Calm

Noise

- Can cause stress
- Which noise is relevant?
- Electrical equipment noise can be overwhelming
- Use of the right music can reduce agitation – optimum time is 20 minutes per hour
- TV

Pace

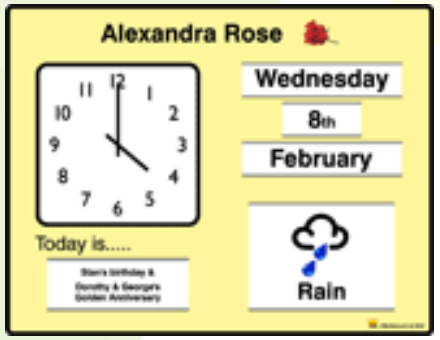
- Care staff need to slow down as rushing can cause agitation

Stimuli

- Activity areas to reduce over stimulation

Predictable and Making Sense

- Door colours e.g. red for toilet doors
- Good signage / objects of reference at right height (4ft)
- No surprises – are items on display, easily found?
- Picture timetables, rotas
- Depth perception – patterns, colours, steps, bath mats, door bars
- Matt floor surfaces
- Colour
- Fire Hydrant boxes are an issue



Picture prompts

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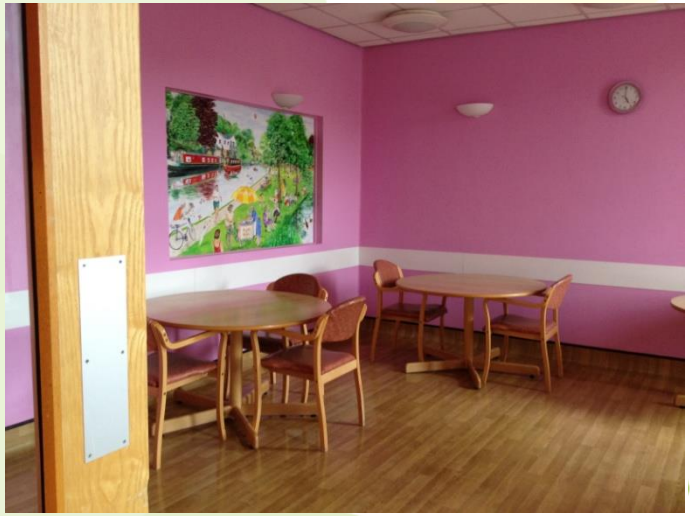
Door & Drawer Sticker Pack

Activity Board - dry-wipe

Colour

- Need good contrasts
- Light reflecting colours
- Use colour to define spaces



Familiar

- Use of traditional equipment
  e.g. taps, lamps, chairs
- Avoid long corridors
- Pictures

Suitably stimulating

- Need to have a level of stimulation that does not leave the person alone and feeling ignored
- Small quiet areas
- Range of peaceful, calm memory appropriate activity
- Able to be involved with tasks of daily living
- Activities suitable from previous lives / male oriented
- Outside views
- Access to outside space – 20 minutes per day for good health re Vitamin D

Safe

- Doors are made to go through
  - Fire doors
  - Handrails

- Floors need to be level, including garden surfaces

Bedrooms

- Finding it!
- Good night sleep
- Colour contrasts – bedcovers, furniture, carpet
- Blackout curtains
- Reduce patterns
- Traditional lights
- Coverable mirrors
- Dementia friendly wardrobes
- Personal items

Night time care

- Night lights or lamps activated by movement sensor
- Commodes may be useful if a person cannot reach the bathroom, but they may forget what it is for or not recognise it.
- Avoid waking the person up during the night to see if they have been incontinent of urine.
- A sensor mat in the bed can help
- Modern body-worn continence products will contain urine and protect the skin for the night.
- Waking night staff should feel free to wear a dressing gown.

Bathrooms and toilets

- Finding them from seating areas / bedrooms
- Contrasting colours will assist a person with dementia to use bathroom facilities.
- Toilet seats, handrails and towels should all be easy to identify.
- A bar of soap (which should be a different colour from the sink it sits on) can prompt a person to wash their hands when they might forget otherwise.
- Bathrooms should be furnished and decorated to promote a pleasant experience. Avoid a sterile hospital-like appearance that is pale and where it is hard to see things.

Activities and Interventions

- Taking part in occupations (self-care, productivity and leisure) define who we are and provide meaning and pace to our lives.
- The need to engage in activities that have purpose and meaning to us as individuals, is a basic human ‘drive’ that does not diminish or disappear as we age.

Early stage

- Support the person to engage in activities to the best of their ability for as long as possible.

Mid stage

- Adapt an activity/task e.g. breaking activities down into steps.

Late Stage

- Process of engaging in an activity becomes more important than the end product. If the activity has a clear impact upon the wellbeing of the person, it is meaningful and therapeutic to them.

Suggested interventions

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Kalsy –Lillico et al., (2012) reproduced in Watchman (2014).

Early Stage	Early–Middle stage
Board games: card games such as snap are good, as are large sized dominoes Ball games: throwing soft balls to each other, standing or sitting Discussion: about people, places and things Relaxation: progressive relaxation, massage or aromatherapy activities Arts and crafts: painting, coloring in, making bean bags, poster End-product activities – anything where there is an immediate end results such as flower arranging, drawing, cooking, baking Use visual planners to structure activities/day	Music – play something that resonates, is liked by the person and has a good bass and beat Dance – chair dancing is good, swaying and rocking in time to music Art and 'pottery' – working with dough, clay, plasticine or sand Movement – guided walks, progressive relaxation Drama Reminiscence – using familiar items, mementoes touch, taste, smells, sounds, pictures or photos that reminds people of times gone by Storytelling – talking about old friends, stores about special times, memories or what's on TV Spiritual or religious activity

Middle Stage	End Stage
Movement and exercise – can be done standing or sitting Multi-sensory environments – use lights, sounds, smells, touch, Snoezlen Massage – hand and feet spa treatments One-step cooking tasks – such as mixing items, peeling food One step gardening tasks – such as watering plants, digging pots One-step daily living tasks – such as plumping up cushions Walking – along routes that are circular with focus points Stacking and folding – clothes, papers and magazines Soft toys – touch can help anxious feelings Baths, bubbles, balloons – remind people of fun	Smiling and laughing – don't underestimate this as an activity Singing – humming along to popular tunes, radio jingles or TV adverts Stroking – positive touch of people and objects that have different textures Gentle rocking – can relax and establish physical contact Holding – as above Cuddling – as above

Anxiety and stress reduction

- One of the first symptoms often seen, caused by the effects of disturbed encoding, is anxiety.
- Recognise anxiety and look for solutions
- Use a variety of techniques:

  - reassurance and verbal reminders,
  - visual aids to remind the person where they are going,
  - relaxation techniques that are already familiar to the person

    aromatherapy

    breathing exercises

    imagery

    visualisation exercises.

Life story work

Kerr & Wilkinson (2005) said of people with dementia that 'if you do not know their past then you cannot understand their present'

- Need a thorough knowledge and understanding of the person and their history.
- The process of talking to people about their memories, collecting objects and pictures are the important aspects, rather than the final end product. Helps with engagement of family members and friends
- Use regularly to help reduce anxiety and give the person and staff a sense of the person and who they are rather than focussing on the dementia.
- The Life Story can help staff to understand what the person is referring to when they remember things from their 'rollback memory', and this helps them to respond more sensitively.
- For the person with a learning disability, a lifestory book will remind any new carers that behind the debilitating illness is a person who enjoyed certain things in life.

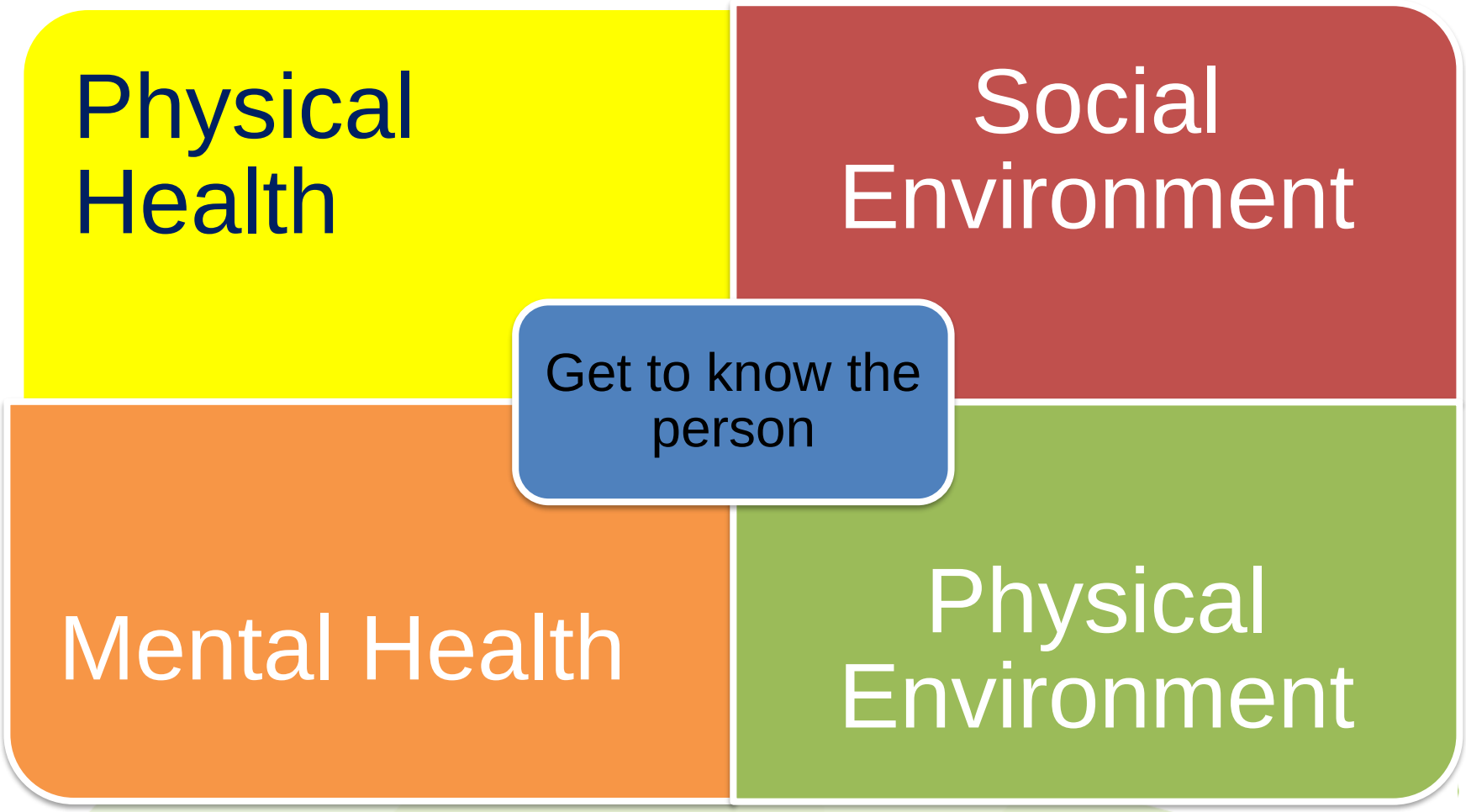
Reminiscence

- Staff and carers need to remember that people compensate for their deterioration in functioning by making greater use of remaining abilities (e.g. earlier memories).
- This may mean that the person finds comfort in activities and objects from their childhood.
- Reminiscence work can help the person with learning disabilities and dementia to find anchors with their past and to help steady and engage the person
- Use music, objects, activities as a way of engaging people.

Reality orientation v validation

- Reality orientation means finding ways to orientate people to reality
- In early stage dementia, reality orientation clearly has its place when people are ‘nearly oriented’.
- Use cues, gentle reminders, photos and pictures to help the person to engage with the world around them in a meaningful and stress-free manner.
- As the dementia progresses, the person with dementia does not remember events that have happened in the past as their memory ‘rolls back’ to an earlier time.
- This frequently results in the person asking for people or about places that are no longer alive, or part of their lives.
- It is now accepted that ‘telling the truth’ is not the best approach.
- We need to validate the person’s feelings without making them more stressed
- Barbara Pointon recommends that if the person is unable to enter our world, then we must enter their world and affirm it.

Behaviour that challenges



Understanding behaviours

- The problem behaviour may be transitory to the current stage of the person's dementia and not need an intervention.
- The situation should be viewed through the eyes of the person with dementia, i.e. their current reality.
- Continual correction by staff/carers of a false reality (e.g. person with dementia asking when a dead parent will visit) will not reduce their immediate confusion and distress.
- Behaviours may be due to:
  - person to communicate or to make sense of a bewildering environment
  - exacerbation or return of previous behaviours.
  - return to a long term memory that is now inappropriate
  - underlying neurological change,

Managing behaviours

- Simple and practical solutions may work, e.g. a net to catch items thrown out of the window.
- Behaviours may reduce by reducing anxiety and stress. Introduce relaxation, avoid conflict and confrontation. Ask yourself: 'Does it matter?'
- Simple environmental alterations may alter the behaviour e.g. covering a mirror.
- Use usual methods of observing, monitoring, and understanding the function of the behaviour to decide on the best intervention, alongside thorough risk assessment and crisis management plans.

Introducing the QOMID

Quality Outcome Measure for Individuals with Dementia

We wanted to develop a quality of life measure that:

- Could be used with anyone with dementia
- Was stage specific
- Reflected the guidance in the BPS/RCPsych document
- Was fairly quick to administer
- Could be used in any setting
- Could be used to help both evaluate quality of life and plan to improve it

Example of a domain

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
8. DAILY LIVING	The person is able to complete personal care and daily living activities as much as they are able, but without pressure. The person's abilities and additional assistance required to help maintain independence are recognised, and the person is supported appropriately e.g. having increased prompting.	The person is able to complete parts of personal care and daily living tasks that they can do and are assisted as necessary so they do not fail. Their support plan details the additional assistance required to help maintain as much independence as possible in a failure free manner.	The person experiences care that is dignified and respectful of them as a person for all their personal care and daily living activities.
	1 2 3 4	1 2 3 4	1 2 3 4
Evidence for rating?			
What needs to happen to improve the person's quality of life in this area?			

1	2	3	4
This is rarely achieved for this person	This is sometimes achieved for this person	This is mostly achieved for this person	This is completely and consistently achieved for this person

For a

Describing the QOMID

QOMID is Quality Outcome Measure for Individuals with Dementia.

- consists of 17 domains which explore the key areas that ensure that the person with dementia is experiencing a good quality outcomes
- staged for the three main stages of dementia – suspected/ early; mid and late stage.
- although the domains are the same for each stage, the description of quality outcome may change across the stages to reflect the different requirements as dementia progresses.
- Available at

http://dcp-ld.bps.org.uk/dcp-ld/useful-links-and-info/useful-links-and-info_home.cfm

Scoring

- Decide which stage of dementia the person currently falls into, based on current assessment and professional opinion.
- Use the column for that stage of dementia and rate each domain using the following rating scale:

1	2	3	4
This is rarely achieved for this person	**This is sometimes achieved for this person**	**This is mostly achieved for this person**	**This is completely and consistently achieved for this person**

- For each domain, circle the rating at this current time. All domains should be completed. Record the evidence you have used to make the rating.
- If the domain is rated less than 4, specify what needs to happen to improve the person's quality outcome in that area of their life.

Real life example

- James is a 58 year old man with Down's syndrome and in mid stage dementia. He lives in a 6 bedded LD residential home in a complex of 4 homes, which have been through difficult times. It is now more stable and the manager of the complex has now decided that this home will become a specialist LD & dementia home.
- Undertook the QOMID with staff, family and James in March 2013
- Overall score was 57 – good quality outcome

Identified areas of need

	Domain	Score	Actions required
1.	**Person Centred Approaches to Support**	3	Life Story Book needs to be done – assistant psychologist, family and staff
4.	**Consistency of approach**	3	Guidelines for morning and evening routine need to be put on the inside of James' wardrobe door, and all staff informed.
7.	**Orientation**	2	More picture cues are needed. Larger staff picture board, daily timetable, picture menu, pictures for events /shopping
9.	**Carrying out preferred activities**	3	Further favourite activities have been identified from James' earlier years with family. Brother to make James a Shovehappeny board. Outings to Bognor / Wittering. Putting green – Littlehampton. Putting set for garden

	Domain	Score	Actions needed
11.	**Environment**	2	Some work has started but a fuller programme of environmental modifications is needed e.g. red toilet seats, more signage etc
13.	**Health**	3	DisDAT to be completed re non verbal ways of assessing distress for James. More attention to be paid to need for Vitamin D and DH guidance
16.	**Mobility**	3	Shoes need to be checked regularly for fit, and staff to check walking regularly
17.	**Continence**	2	Mattress on bed needs to be sorted Pads need to be sorted – pull ups during the day and flexitab at night Staff to ensure bedtime routine is followed. Toileting programme and monitoring chart to be started asap Community Nurse to follow-up re continence products and funding

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