

# *Addressing our human needs when supporting family members*

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# Overview

- Existential issues that people face
- The lifeworld
- How to access the lifeworld
- Lifeworld-led service example – **Expert companions**
  - work by Mark Holloway
  - where the subjective, lifeworld experience of both service users and providers are combined to form the basis for understanding and service delivery
  - allowing a fully human response within care and rehabilitation services.



# *Traditional approaches to rehabilitation*

- Doing something to help/support people
- Based on our observations of what needs doing
  - Observations –informally seeing what is needed
  - Assessment
  - Measurement
- To improve things in the future
- Professional has the expertise and person and family living with ABI learn how to manage their new situation



# *Traditional approach*

- Very good for
  - medical
  - physical
  - Practical observable issues facing people
  
- However emotional and social aspects not always addressed
  
- Can leave the person and their family members feeling very isolated

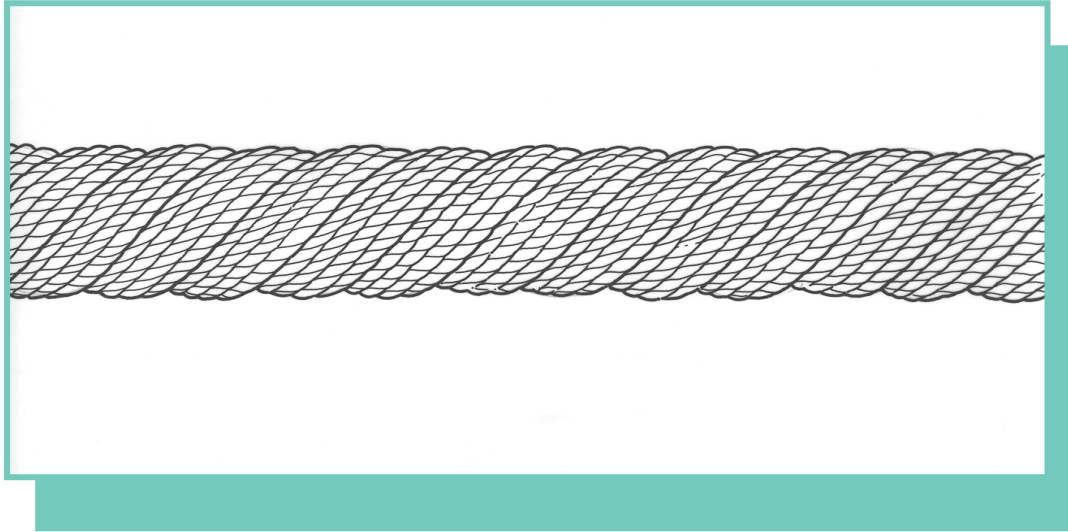


# *Social - emotional consequences -deep existential challenges*

- Taken for granted assumptions about the world our lives , reality very suddenly challenged
  - **Deep questions**
  - Who am I now ?
  - How do I fit into life ? –the world ?
  - How do I live a meaningful life ?
  - How can I trust the world again ?
  - How do I make sense of what has happened to me ?
- 
- This occurs for person following ABI and all members of their family
  - These questions are rarely recognised and even less likely to be addressed
  - **Our area of interest - How can we access and work at this existential level ?**

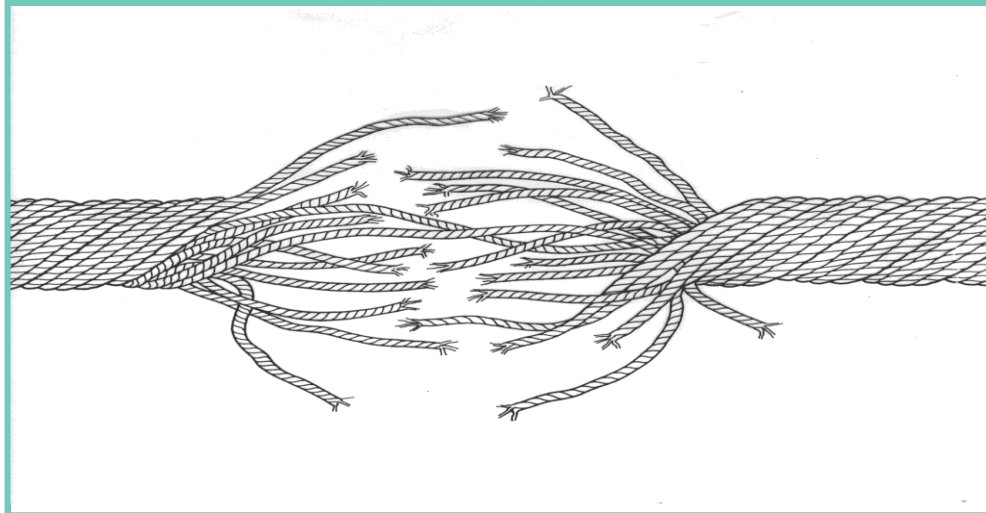


# *Life Thread Model*

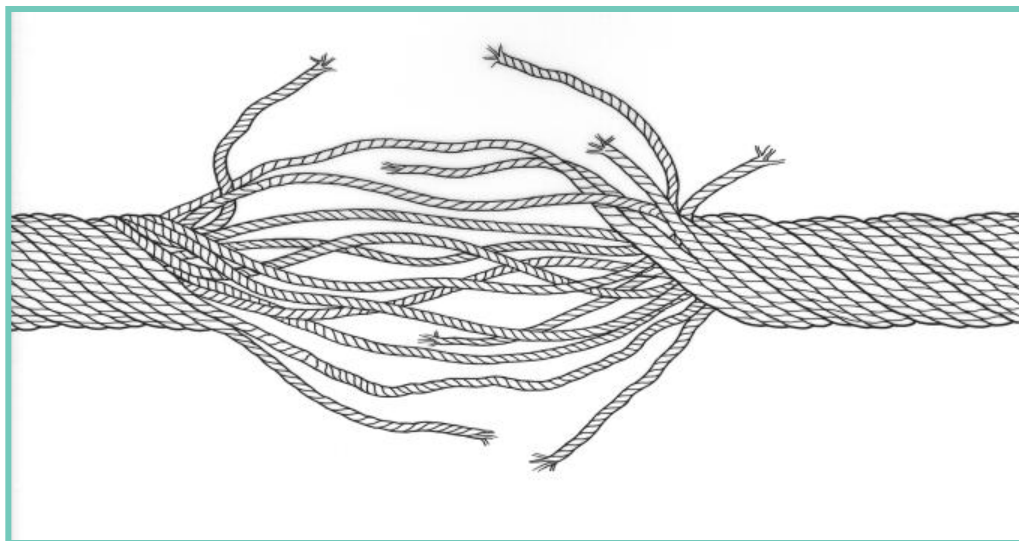


Ellis-Hill C, Payne S, Ward C (2008)

# *Life threads frayed*

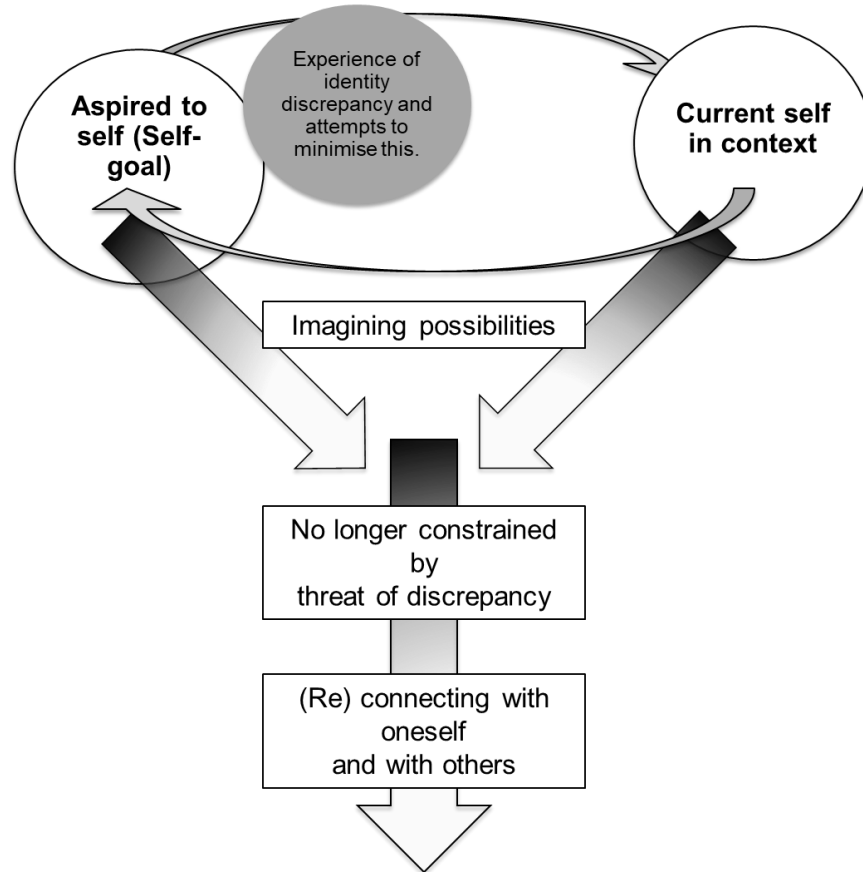


## *Joining up life threads*





# *Self-discrepancy Ownsworth and Gracey (2017)*



# Interest in lifeworld and humanising practice



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# Lifeworld

- The lifeworld is a concept developed by Husserl (1859—1938) philosopher and phenomenologist
- The lifeworld can be thought of as the horizon of all our experiences, in the sense that it is that background on which all things appear as themselves and meaningful.

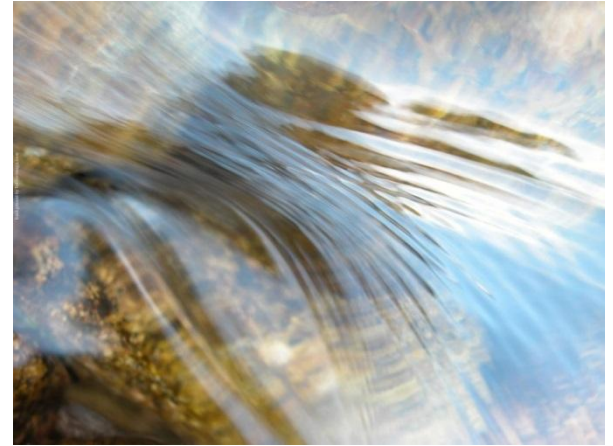
(Galvin and Todres 2013)

- Our everyday flow of life as we experience it
- Our subjective experience of life and our worlds
- *What our life feels like from the inside out*



# *Lifeworld assumptions*

- In flow of life – how we experience the world before we think about about it -**things are not separated into categories** until we start thinking about them
- We experience life through our body – we use **embodied knowing** (which is very precise and subtle) as well as conscious intellectual knowing **Felt sense Gendlin**
- We are **creating and re-creating meaning** in our lives and world moments by moment - fluidity and creativity
- Where does my experience start and your experience end ? –we can experience **shared horizons**
- **Connection to deep knowing and sense of wellbeing**



## *Wellbeing – connection - beyond words*

- Experienced in many ways – when sitting on a beach looking at the sunrise
- Mark Nepo (2011) ‘ If we are quiet enough and open enough we can drop into the fabric of existence ‘ and ‘from that knowing connection , ..we can feel the tug and pull of everything alive’ p14,
- Wellwood (2014) describes this place as ‘open ground’
  - a place we all share,
  - beyond time and space
  - beyond concepts
  - experienced as a sense of aliveness, joy and wellbeing.



## *How can we access our lifeworld resources ?*

- Be present
- Be open and curious
- Trust process
- Create safe space
- Invite shared learning



# *How can we access the lifeworld ?-1-Be present*

- In order to use our embodied knowing and receptivity we need to be in the present
- In our bodies
- Not just in our thoughts –these are always linked with either the past or the future
  - Arts-based approaches
  - Being in nature
  - **Consciously centring yourself /pausing**



# *How can we access the lifeworld – 2-Be open and curious*

- Open to what person wants to share with you –sense of ‘not knowing’
- Do not have pre-determined agenda
- Do not assume their world is like your world
- Be curious about what the person’s subjective world is like
- Non-judgmental – their experience cannot be wrong – it just is





## *How can we access the lifeworld ?- 3 Trust in allowing*

- No predetermined outcomes
- Sense of letting go of control and allowing something to happen.
- As a professional this feels very strange
- Enter shared human space
- Access embodied knowing
- Builds trust between people



## *Access to Lifeworld – 4- create safe space*

- You create a safe space for people to explore their subjective experience of their worlds alongside you
- When you stay with people's experiences - both their vulnerabilities and possibilities people can feel this
- When this space is shared ....
- People feel seen
- People feel recognised



# *Access to Lifeworld - 5 –shared learning together*

- When in a safe space
- Shared learning takes place
- Both are experts in own experience, for a health or social care professional *part* of their experience is professional knowledge
- Agenda shared by both parties



# *Access to lifeworld 6 Connection - creativity - possibility - confidence*

- When this space is held in light, playful way
- Can stay connect to embodied resources - and what is important for us in our lives
- Allows use of imagination and creativity – can see new possible futures
- Generates the energy to try new things out and see what happens, become an explorer
- Develop confidence in ourselves and our lives



# *Embodied Relational Understanding (Todres, 2008)*

- **Being** –Embodied
  - We gain access to the complexity of our pre-verbal embodied resources (*Gendlin, 1962*)
  - We can use our empathic imagination (*Galvin and Todres, 2010*)
  
- **With**
  
- **'That'**

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- **With** – Relational –sharing of responsibility –creates connection - bonds
- **'That'** – Understanding
  - Integrated understanding beyond rational knowing
  - A living/ 'alive' situation, - specific to the moment, which can never be fully known, always in excess

# *Service provider-relationships*

- Focus on the nature of **relationships** as much as tasks
  - **Open**
  - **Relaxed**
  - **Playful**
  - **Celebratory**
  - **Safe**



# *Expert companions*

- Concept developed by Dr Mark Holloway
- As a result of his PhD work
  - Online survey 110 relatives
  - In depth interviews with 16 relatives
- **Expert** – specialist vs generalist knowledge is needed
  - ABI/systems
- **Companion** – empathic understanding and humanity



# *Services not supporting relatives –invisible*

- Online survey relatives - 110 respondents
- Severity of ‘invisible’ consequences of the ABI greater than physical impairments
- Compounded by reduced insight on the part of the person suffering the ABI

## **Experience of services**

- 3 /69 wholly positive , majority either mixed or wholly negative.
- **Positive** - specialist ABI services, independent and highly specialised brain injury rehabilitation units, brain injury case managers, specialist litigation solicitors—long term support .
- **Negative** ‘fight’ to navigate the system, lack of information, delay (sometimes of many years) in accessing services; lack of involvement; and no overall co-ordination
- **Lack of understanding of what relatives are going through**

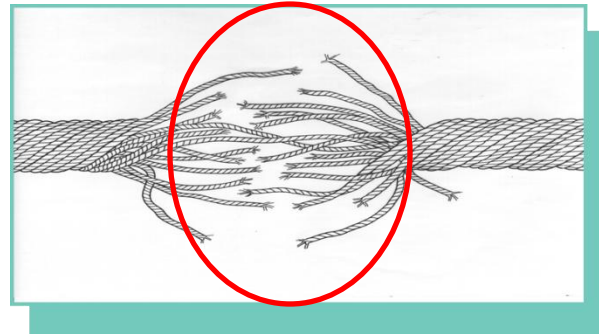


# *Existential challenges facing family members*

- Taken for granted assumptions about the world our lives , reality very suddenly challenged
- **Deep questions**
- Who am I now ?
- What's going to happen ?
- How do I cope ?
- How do I make sense of what has happened to me ?
- **Perpetual uncertainty**
- **Ambiguous grief**



So what helps ?



## *People who are empathic*

- Feeling that the professional understands or at least makes every effort to understand the experience of the participant

*“The social worker actually is another person who has been amazing, very young girl, but she just really understands and really gets it”. (04)*

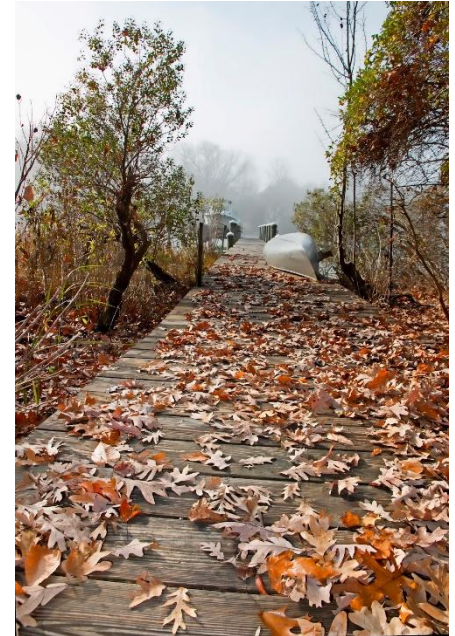
- There were few professionals who had managed this, but those few were highly valued.



## *Being with –beyond only doing*

- Practitioners who are seen to care, even if sometimes they were also unable to provide an answer:

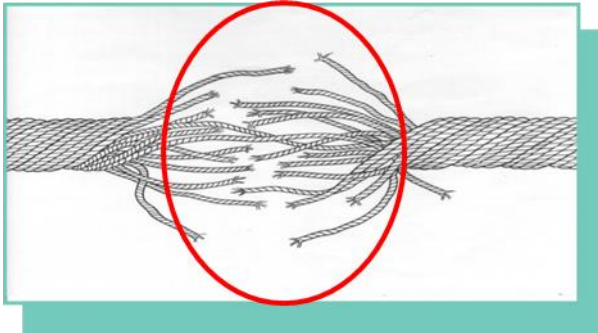
*I think the parents really need somebody that they can talk to. It's not somebody who is going to give you an answer, it's just somebody to understand and say, "Yes, I know." (16)*



# Acknowledging uncertainty

- Practitioners who could acknowledge and felt OK with uncertainty

*He also helped us – he put a plan in place. He was like, “You know–” he just gave us really good advice. He was like, “Your life isn’t going to be the same” and this was the first time anyone had ever said this. (08)*



# *Flexibility - changing the service to meet the need*

- Services /people who can be flexible and respond to needs
- Despite being in a highly specialised unit, person repeatedly and violently smashed furniture and toilets, but the centre found ways to adapt:

*‘Their way of looking at it was, “well, what’s the answer to this?”’ A stainless-steel toilet was imported from overseas to replace the broken porcelain ones, demonstrating that ‘Their philosophy was we will build it right, what he needs.’ (13)*



# Shared moments of humanity

- Practitioners who can share vulnerabilities

*He asked me what the behaviours were that were upsetting people. I says, “Well, he laughs inappropriately” and I always remember this, he says, “Well,” he says, “in here, I laugh inappropriately,” and he started laughing. ‘Course our we went into hysterics. Three of us were sitting in his office with tears dripping off us. And I just – you know, you just met somebody that is clued in. (14)*



- This moment of acceptance and connection was remembered and prized decades later
- **Small moments make a big difference**



# *What do relatives say works?*

- Rehabilitation/restoration of function/outcome is only one component.
- The process is integral and central.
- Continuity, knowledge, attitude and availability.
- The humanising co-creation of person-specific knowledge.
- An “expert companion” on a life-long journey.
- Support to develop the new normal. This is a non-linear process, the development of a new narrative, experienced in hope.



## *Valued humanising staff who:*

- Recognised the uncertainty, the unclear and ambiguous nature of the situation, and the centrality of the relative.
- Understood their own lack of ability to “solve” grief and/or the ABI and demonstrated humility accordingly.
- Viewed this as a humane exploration of establishing the new and valued neuro-narrative, a family neuro-narrative.
- Valued hope and did not allow limitations to crush this.
- Viewed this as co-construction.
- Offered to “stand in the glare of the grief” and limit isolation accordingly



# *Accessing the lifeworld – Expert companions*

- **Be present** - share stories, shared own experiences, stay present in the face of grief
- **Be open and curious** – show an ongoing curiosity in interest in what this experience means for relatives
- **Trust to allow** – recognise they do not have all the answers – humility to feel able to see what happens
- **Safe space** -hold space - non judgmental – accept vulnerabilities and possibilities of self and relatives - playfulness, laughter,
- **Shared learning** - share learning about how to move forward and what would work for the relative and their family
- **Connection, creativity and confidence** – develop confidence in being a companion and reducing isolation and relatives develop confidence that they can reconnect with a meaningful life for themselves and their family

# *Lifeworld-led rehabilitation and care*

- Has a very different logic to traditional approaches
- Works at a deep existential level
- Allows people space to create new possibilities, new ways of connecting and living their lives
- Early service examples – powerful
- People are already working in this way
  - recognition to those people
  - Give a language to use
  - Raise profile for importance working in this way
- Early days- Still exploring the best way to support service development



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# Further information

## Website:


<https://research.bournemouth.ac.uk/2013/11/humanising-caring-health-and-wellbeing/>

## E-mail list:


For newsletter and events-contact  
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### Humanising Care, Health and Wellbeing

10 November 2013



Over the last 20 years at Bournemouth University, Professors Kathleen Galvin and Les Todres have developed a coherent programme that integrates health-related philosophy with qualitative research. This programme is summarised in their book: *Caring and Well-Being: A lifeworld approach* (Routledge, 2013). [Click here for a brief overview of this book and some reviews.](#) This focus has been taken up by other researchers, educators and practitioners both within Bournemouth University as well as nationally and internationally.



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- Research Centre: Centre for Qualitative Research
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- Level: LSHS
- Tagged: caring for the elderly | health | health education | healthcare | humanisation | humanisation framework | humanising | humanising health and social care | social care | social work | wellbeing

#### Humanising Caring Health and Wellbeing conference 2018

#### Humanising Special Interest Group

#### Links

- European Academy of Caring Sciences
- International Human Science research conference (IHSC) network
- PIER partnership
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- Prof Ann Hemingway
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*Thank-you !*