

# What does self-care mean from a lived-experience perspective?

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I had been a very busy and outcomes-driven person in my paid and voluntary work.

I worked, studied, played, socialised and cared for my children.

I spent two years severely ill with ME/CFS and struggling to be a single parent, while barely able to move from bed or communicate.

Now I can 'do' something most days, but it is little and slow.

# My body is letting me down

- chronic illness
- chronic pain
- physical weakness
- falls
- inability to manage activities of daily living
- inability to continue physical hobbies
- reduced capacity for carer roles



# My body is letting me down

Self-care

- medication, supplements and daily therapies
- accepting help from others
- using assistive technologies
- expanding non-physical hobbies
- new ways of caring for others
- acknowledging the losses and accompanying grief



# My bedrock is shifting

- retirement from paid and voluntary work
- loss of income
- loss of marriage
- loss of the home
- reduced social network



# My bedrock is shifting

Self-care

- learning to live alone
- adjusting to a smaller home
- accepting having fewer financial choices
- making more of fewer social contacts
- seeking new volunteer roles
- acknowledging the losses and accompanying grief



# My close relationships are changing

- empty nest and living alone
- caring responsibilities for father, aunt, adult son
- double bereavement
- reduced ability to stay in touch with friends and extended family
- new role as a grandparent



# My close relationships are changing

Self-care

- learning to enjoy living alone
- adapting to changes in roles and responsibilities in the family
- changing expectations
- taking time out following bereavement
- new strategies for staying in touch with family and friends
- acknowledging the losses and accompanying grief



# Who am I?

- Knowing that time and capacity are narrowing current and future possibilities
- Loss of hopes, dreams, expectations for the future



# My challenge

- Identity
- Meaning
- Purpose



# My challenge

Self-care

- Things never stay the same
- Turning lived experience of adversity into voluntary work to help others
- Grief and acceptance are not linear

