



# Living with “frailty”: older people’s experiences and the role of the voluntary sector

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1. What have we learnt about older people's experience of frailty?
  2. Wellbeing and "self-neglect"
  3. What can the voluntary sector do?



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[https://www.dropbox.com/s/ozbl1r7xs7si5wq/age\\_uk\\_-\\_understanding\\_frailty\\_1280x720%20%281%29.mp4?dl=0](https://www.dropbox.com/s/ozbl1r7xs7si5wq/age_uk_-_understanding_frailty_1280x720%20%281%29.mp4?dl=0)



# What is frailty?

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- Living with frailty typically means a person is at a higher risk of a sudden deterioration in their physical and mental health.
- Frailty is distinct from living with one or more long-term condition and/or disability.
- Older people living with frailty can be low users of health services until a relatively minor event precedes a major change in their level of need.

Fit for Frailty, 2014



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*“Older patients just want to be able to maintain an element of independence. They’re happiest in their own home.”*

*GP*

*“We’ll have people who are admitted purely to buy some time while their care package gets set up. It’s like they’ve been hiding all this time and then they suddenly get ‘found out’ and their lives get turned upside down.”*

*Ward manager*

*“To me, a frail person is someone like a skeleton that can’t move.”*

*Frailty research participant*



Ipsos MORI



UNDERSTANDING THE LIVES OF OLDER PEOPLE LIVING WITH FRAILTY  
A QUALITATIVE INVESTIGATION

IPSON MORI FOR AGE UK  
MARCH 2014



Britainthinks

**Frailty: Language and Perceptions**  
A report prepared by BritainThinks on behalf  
of Age UK and the British Geriatrics Society

June 2015



**I'm  
still  
me**

*...a narrative for  
coordinated support  
for older people*



UCL Partners



ageUK  
Love Older Life



# Living with “frailty”

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| Independence and control                                  | Support and assets                                     |
|---|--|
| Small changes tread fine line between control and support | Small sample > wide variety of needs and circumstances |
| Constant negotiation                                      | Generally happy with services received                 |
| Safeguarding can be an important factor                   | BUT low aspirations for what was possible              |
|   | Carers needs rarely considered                         |



# Living with “frailty”

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| Adapting to life changes  | Loneliness and isolation            |
|---|-------------------------------------|
| Minor changes to home were accepted                               | Signs of depression and loneliness  |
| Larger changes a much bigger challenge – some in denial           | Not necessarily socially “isolated” |
| Impact on others a bigger spur to recognising they needed support | Peer relationships most missed      |
|   | Physical losses <> emotional losses |



# What older people want from services

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# But do they seek help?

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- First instinct is to find their own solutions
- ‘Trigger point’ - people often recognise they are ‘struggling’ – some open to support
- Medical professionals are not naturally seen as the first port of call
- HCPs highly aware of this barrier, but find it difficult to overcome in practice

*“Why on earth would I tell my GP it’s taking me longer to do the ironing and I can’t get out into the garden any more?! He’s a serious doctor who I go to when I’ve got an ailment, he doesn’t need to be bothered with that rubbish.”*

Female, 73, South

# “I” statements

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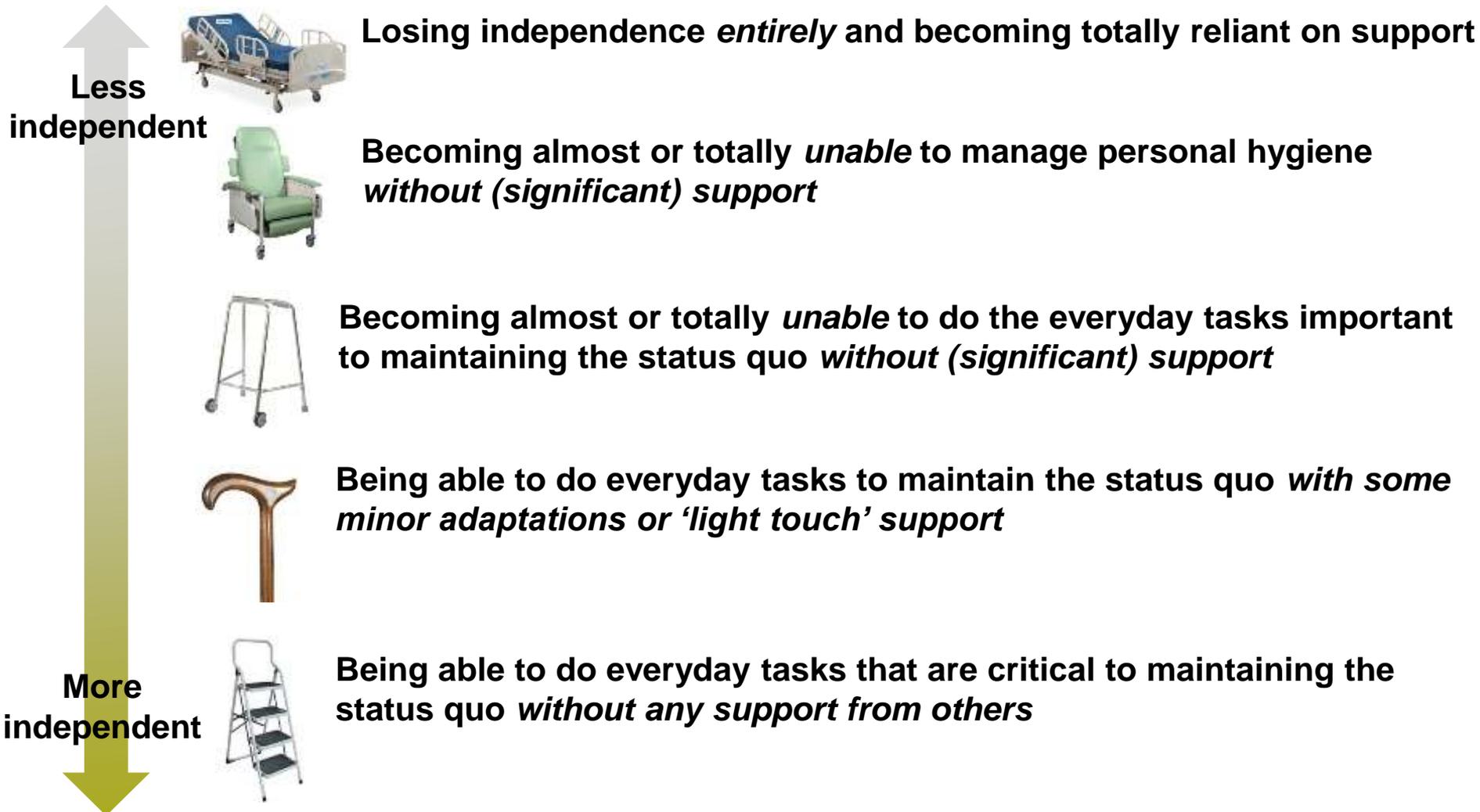
- I can build relationships with people who support me
- I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me
- Taken together, my care and support help me live the life I want to the best of my ability
- **I am recognised for what I can do rather than assumptions being made about what I cannot**



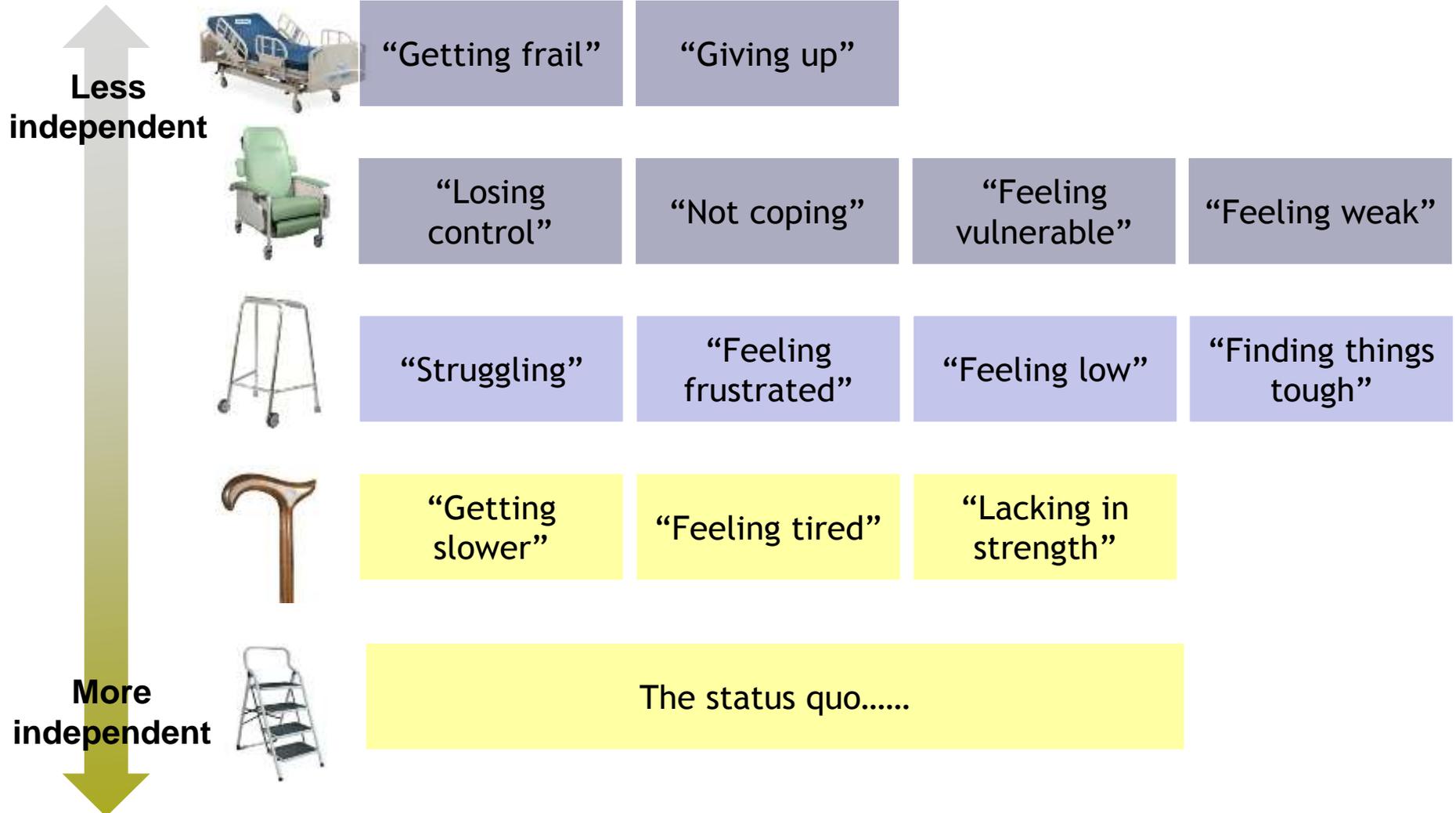


# How does it *feel* to live with frailty?

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# And emotional language matches up



# “Self-neglect”?

At risk of self-neglect

High levels

Safeguarding

*Years ago in the summer I would have a shower before I went to work and a bath when I got home. Now I bathe and wash my hair about twice a week.... Other than that I might do a strip wash or baby wipes, that sort of thing.*

*My health? I think it's pretty awful. I'm always in pain. It's been a year now, and that's a very long time for an ulcer and it just won't heal.*

- Resistant to help
- Reluctance to ask for help
- Individual meets the criteria for Section 42 of the Care Act

# Concepts of frailty

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| Biomedical                      | Lived experience       |
|---------------------------------|------------------------|
| Risk                            | Change/transition      |
| Deficits                        | Fear [of implications] |
| “Unsuccessful” ageing           | Imbalance              |
| Compliance                      | Adaptation             |
| Outcome of unhealthy behaviours |                        |

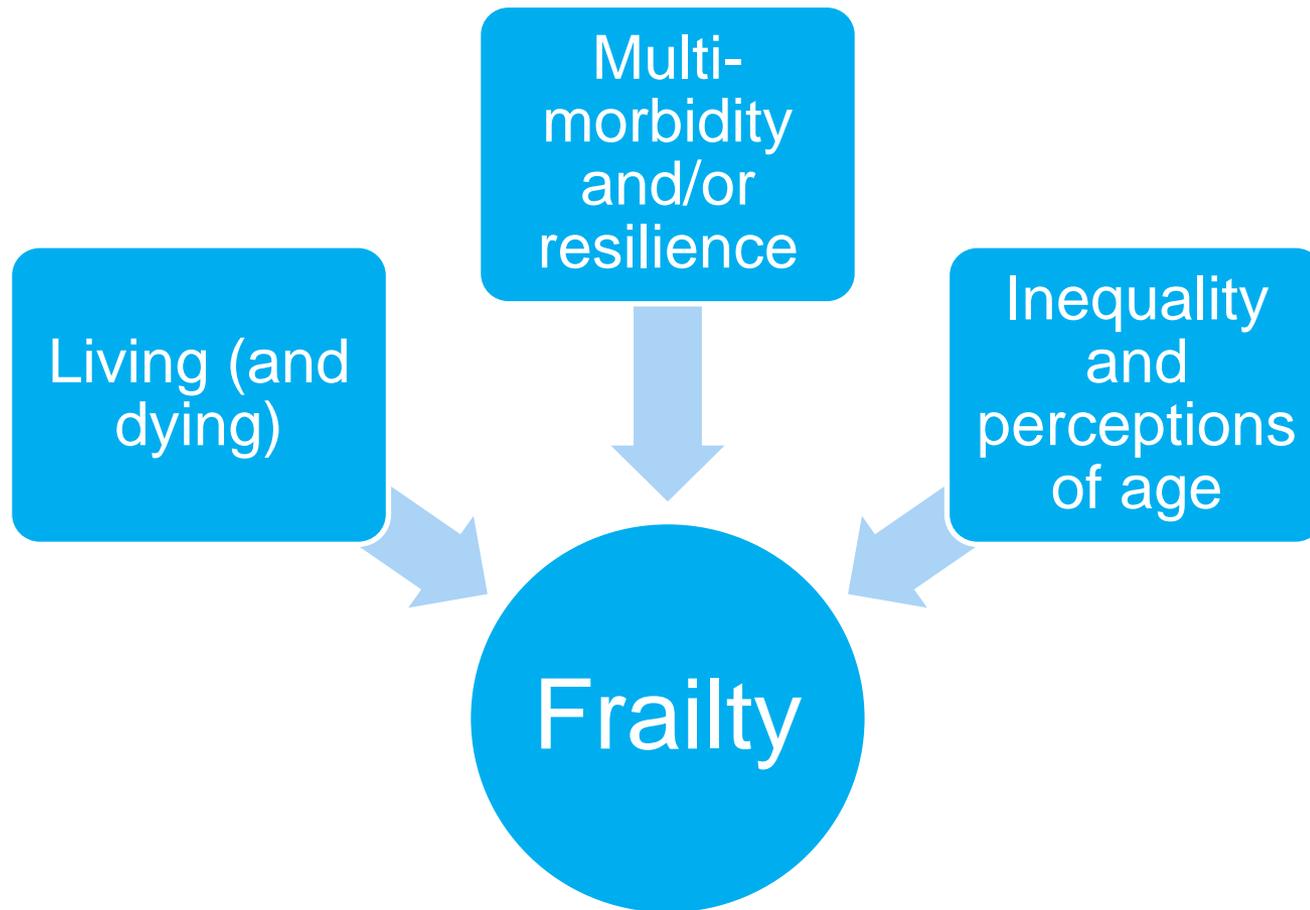


# A “problem” for public policy?

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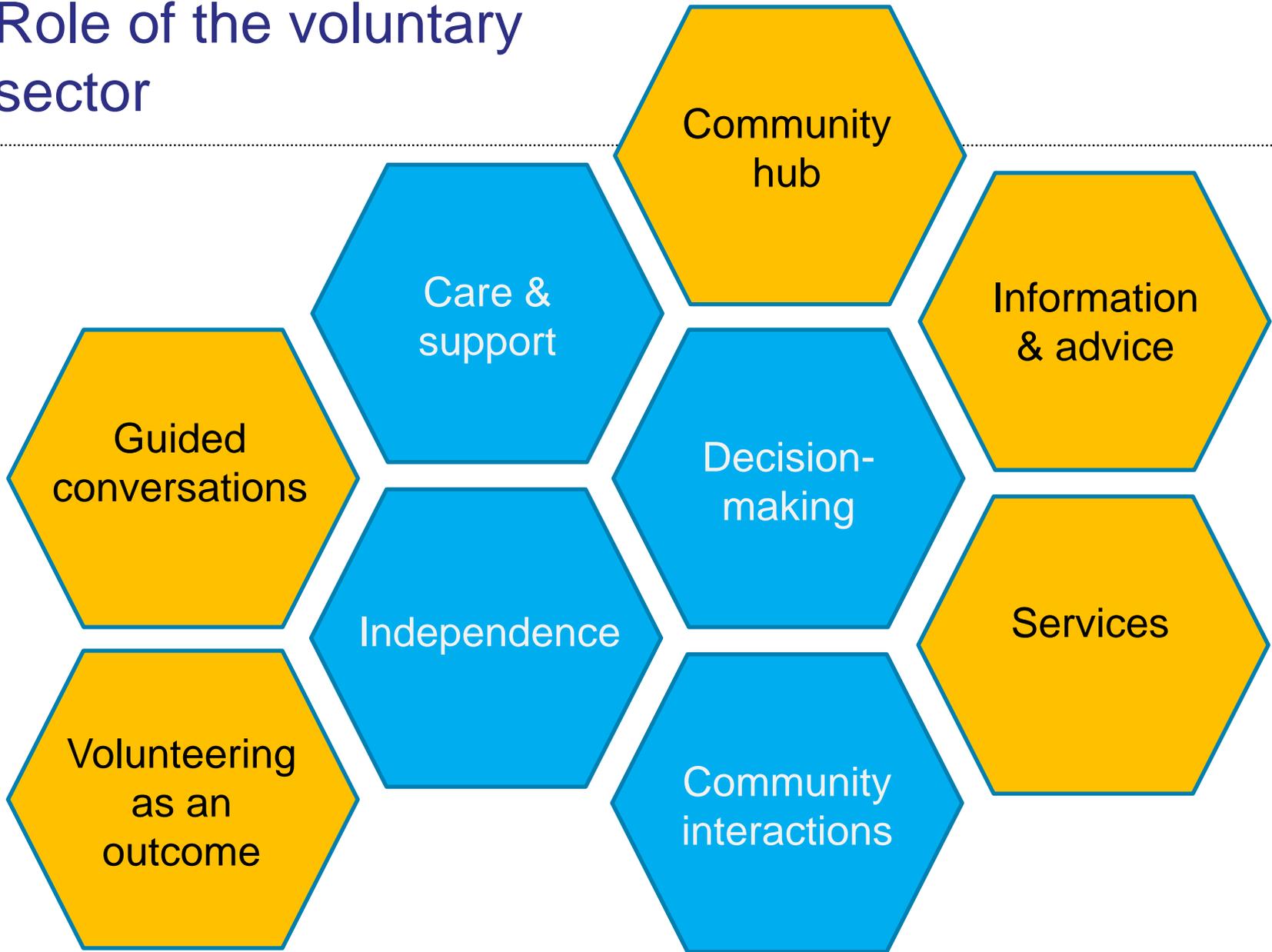
- 2005-2015: Up to 171% rise in ACSCs
- 2010-2015: 21% rise in A&E attendances (60+)
- 2010-2016: 182% rise in DTOC waiting for home care
- Cost of emergency readmissions = £2 billion
- People over 85 = 8 days longer in hospital than under 65s
- Half of avoidable bed days = people over 75
  
- **Not a burden, but the face of avoidable failures**





# Role of the voluntary sector

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# Mr Hussain's story

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- 74, Parkinson's and co-morbidity
- Felt isolated, unable to walk unaided

## *Identified through GP, Age UK worker visited*

- Benefits check – eligible for attendance allowance
- Arranged OT, adaptations made to house
- Started on exercise programme to improve balance and prevent falls
- Computer lessons to complete a book he'd handwritten



# Mary's story

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- 79, recent fall, osteoporosis and arthritis
- Needed optometrist and dentist but afraid to use public transport
- Drowsy and couldn't use even local amenities

## ***Identified following fall, Age UK worker visited***

- Co-ordinated the falls, OT and physiotherapy teams
  - Worker helped Mary to attend appointments
  - Medicines review resolved her drowsiness
  - Helped her get a year's refund from a utility company
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# In summary

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- “Frailty” synonymous with very old age, malnutrition and end of life
- “Frailty” framed through everyday tasks and life style issues –***how people feel*** when and if they become more difficult
- Desire to be independent is both a barrier and an opportunity
- Voluntary sector can play a role in closing the circle
- Identifying needs as well as wants



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