

# Supporting older people & their carers: exploring the value of adopting a 'social' lens

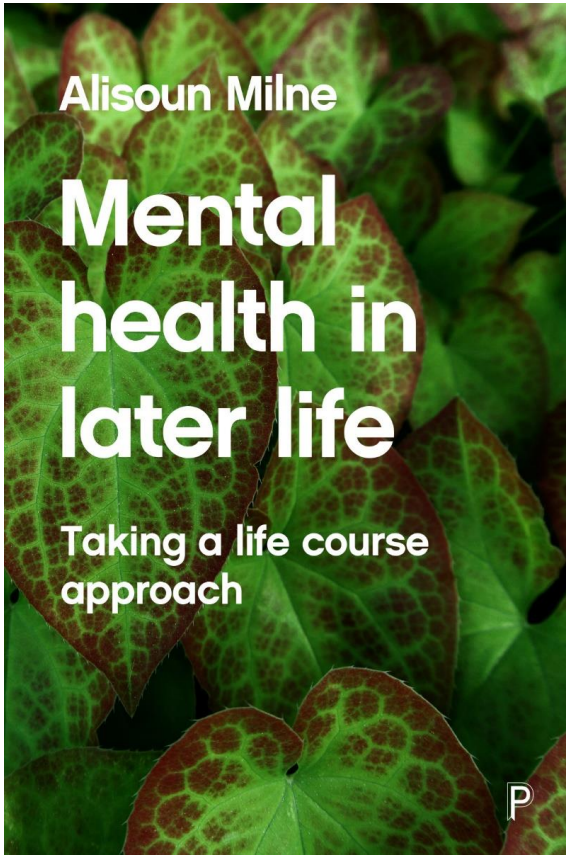
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# Mental Health in Later Life

## Taking a Life Course Approach

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Focusing on mental health rather than mental illness, this book adopts a lifecourse approach to understanding mental health and wellbeing in later life.

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*“I cannot think of anyone better equipped to take on the challenge of exploring the complex topic of mental health in later life than Alisoun Milne. She combines academic knowledge and research with her roots in social work, her capacity to stimulate critical thinking and her commitment to addressing inequalities and promoting social justice.”* **Prof Tom Denning**,  
University of Nottingham

**Prof Parker’s** review, in the *British Journal of Social Work* (Jan 22):  
*‘Some books are simply of their time and Milne’s Mental Health in Later Life is one such work. It is a tour de force of many years of academic scholarship and research. It is destined to become a classic in the field and a reference point for scholars...’*

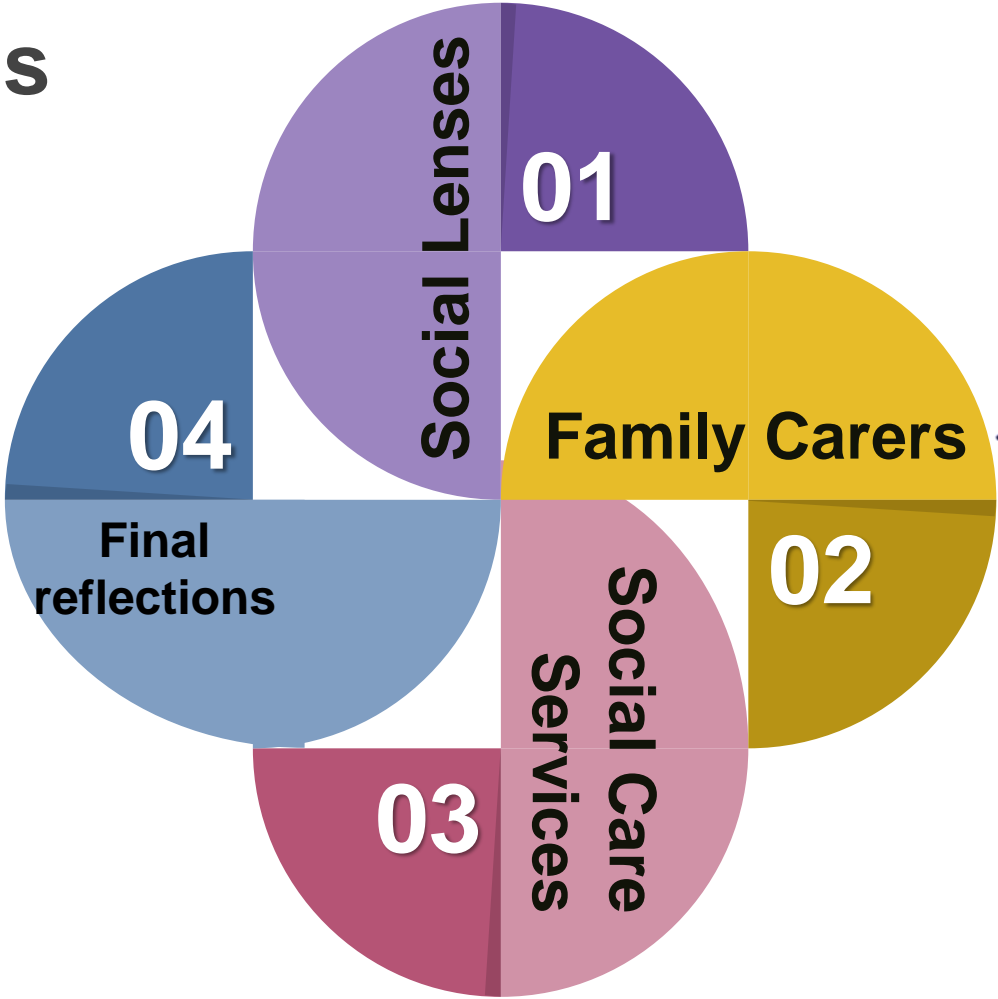
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Drawing together material from a number of different fields the book analyses the meaning and determinants of mental health amongst older populations and offers a critical review of the lifecourse, ageing and mental health discourse for students, professionals, policy makers and researchers.

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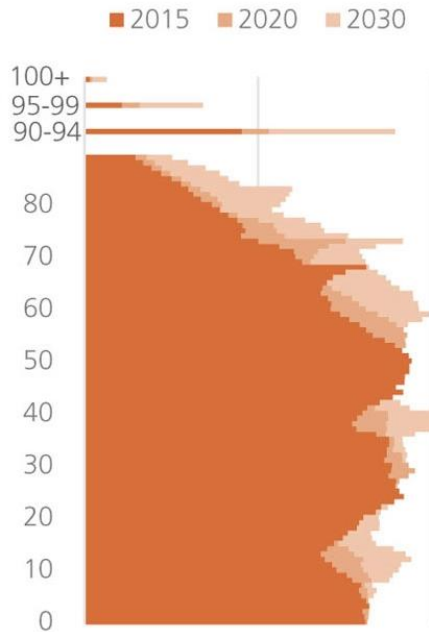
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# Aims





# Context: Socio-Demography



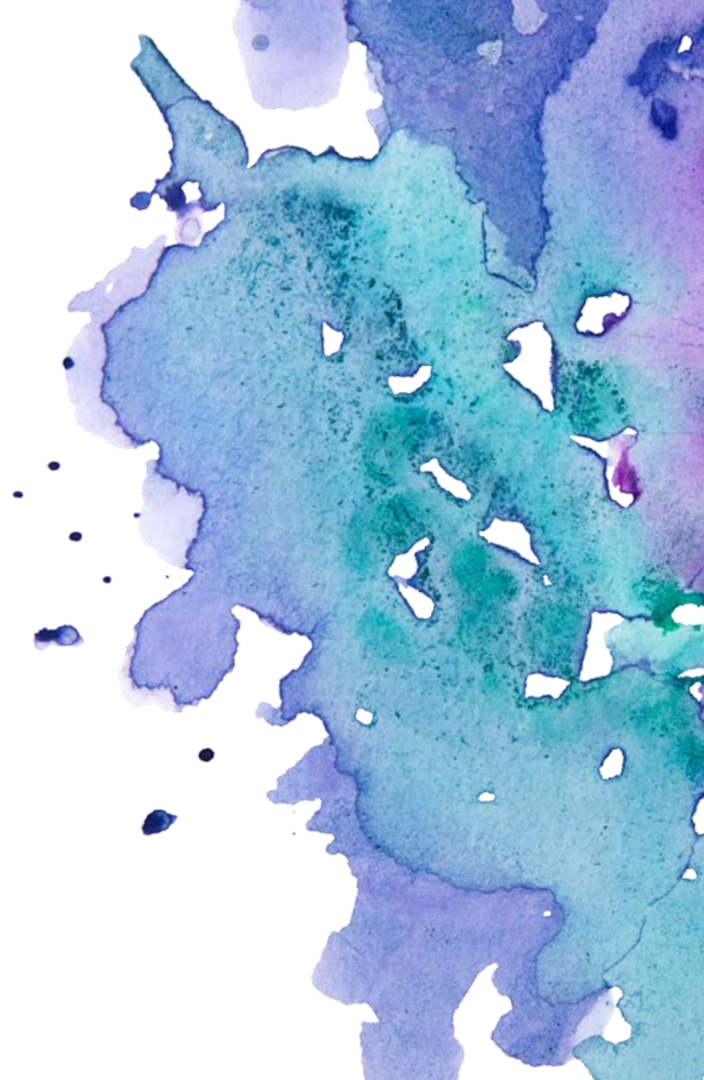
- × Ageing population & particular increase amongst those aged 85yrs+
- × More older people living with chronic comorbid conditions
- × 8m+ people in England living with 3 or more long term conditions: 'frailty' (Age UK, 2020)
  - × Sarcopenia estimated to affect 11-50% of people aged 80 yrs+

# Context: Socio-Demography (2)

- x Dementia: 920k now, 2m by 2051
- x Increase in the number of older people facing situations characterised by change, risk, transition, ill health, complexity & uncertainty
- x Over a third of UK's 10.5 million carers are older people (Carers UK, 2021)
- x Older popn is increasingly diverse & heterogeneous (e.g. more older people living alone, no children, higher numbers from BAME communities)

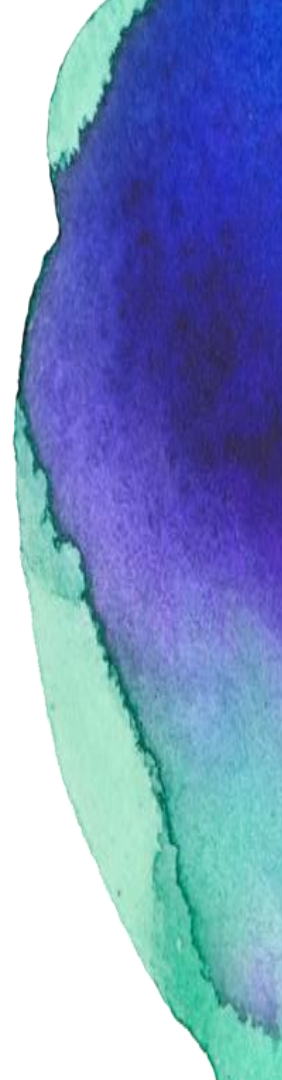
**Socia Lenses**

**01**



# Health & Social Inequalities

- x Marmot's (2010, 2016) seminal work concluded that **health inequalities are a product of social inequalities** - the range of interacting factors that shape health and well-being
  - x Social inequality refers to the unequal distribution of resources - such as power, wealth & income - and opportunities (related, for example, to health, education, employment)
  - x Social class, gender, ethnicity and age are all sources of inequality
- x Clear evidence of large, and widening, inequalities in the older population arising from lifecourse and age-related inequalities

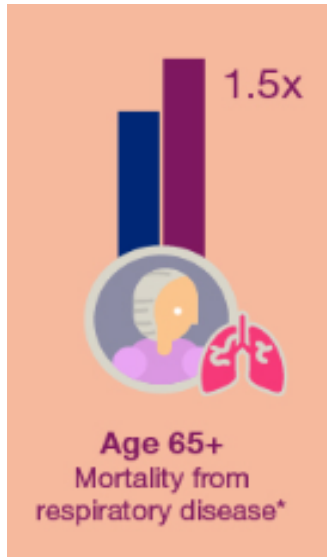


# Health & Social Inequalities (2)

- × Legacy of LT exposure to socio-economic disadvantage is strongly correlated with poor health outcomes including shorter life expectancy & shorter healthy life expectancy

A female born in Glasgow can expect to live 12 yrs fewer than her counterpart born in Kensington & Chelsea: 14 yrs difference for men

Close relationship between SE status and frailty *and* higher levels over time (Tomkow, 2018)



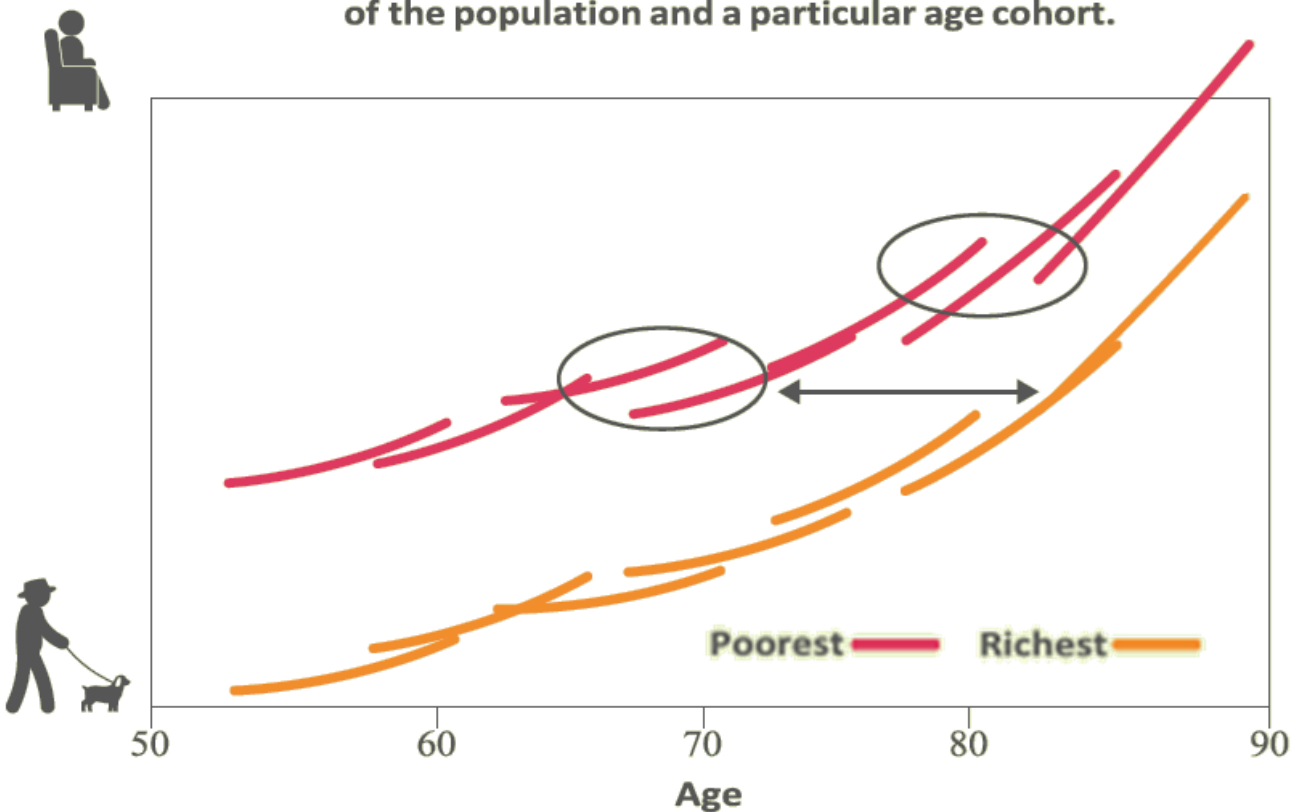
Comparison between **the most** and **least** deprived deciles in England

■ the most deprived decile (times higher) ■ the least deprived decile



# Increase in frailty for different age and wealth groups

Each line represents the poorest or richest third of the population and a particular age cohort.



# Dementia 'risks': lifecourse & inequalities

- x There is growing evidence that dementia is an outcome of an *accumulation of life course risks* over many decades (Manthorpe & Iliffe, 2016):
  - x The *Lancet Commission on dementia* suggests that 35% of all dementia cases could be prevented if 9 modifiable risk factors were fully eliminated: low levels of education, hearing loss, hypertension, obesity, smoking, depression, physical inactivity, social isolation and diabetes (Livingstone et al, 2017, 2020)
  - x Mixture of structural issues related to the life course such as poor education; mental health issues such as midlife depression; and physical risk factors such as diabetes and obesity that are part about lifestyle and part about life course: *a number of risks are linked to social inequalities*

# 'Being' frail vs 'feeling' frail



- × Grenier (2006, 2012) makes a distinction between 'being' frail & 'feeling' frail:
  - × The former is often determined by a clinical assessment whereas feeling frail relates to the older person's emotional responses to illness & impairment = socially determined experiential status
- × Older people are aware of the psychological and sociological risks of identifying as 'frail' (Tanner, 2010; Pickard, 2018)
  - × Lower levels of psychological wellbeing can be both a cause and consequence of doing so
- × Older people, even those who are 'frail', resist this label; can be interpreted by them as evidence of a 'failed' or 'frailed' old age (Gilleard & Higgs, 2010)

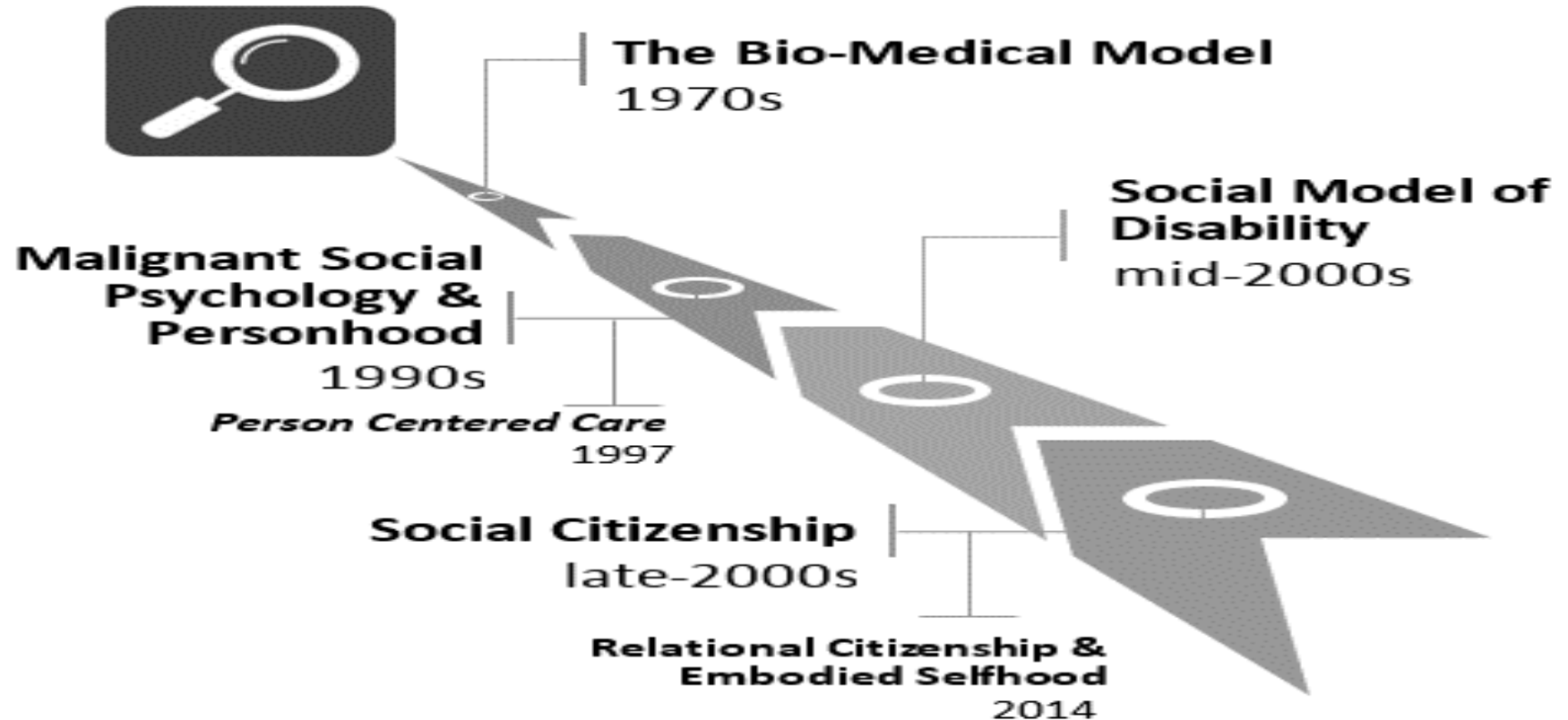
# Taking account of 'feeling' frail



- Appreciate the role played by lifecourse risks: frailty is more complex than a narrative of 'old age'
- Lived experience of frailty tends to lie outside the optic of the health care system
- Support that is sensitive to the person's emotional journey not only reduces anxiety but helps to normalise the psychological processes that accompany adjustment to frailty (Grenier, 2012; Milne, 2020)
- Building a bridge between the medical/functional approach (often) taken by services and the emotional, meaning-making approach taken by older people themselves (Lloyd, 2015)



# Conceptualising Dementia: The Widening Lens (Milne, 2020)



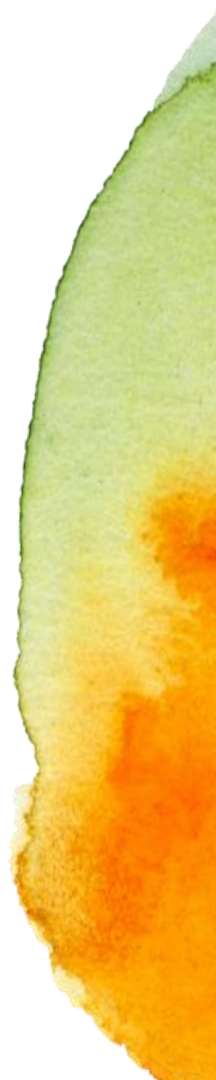
# A multi-dimensional model for contextualising dementia: a social citizenship approach (Bartlett and O'Connor, 2010)

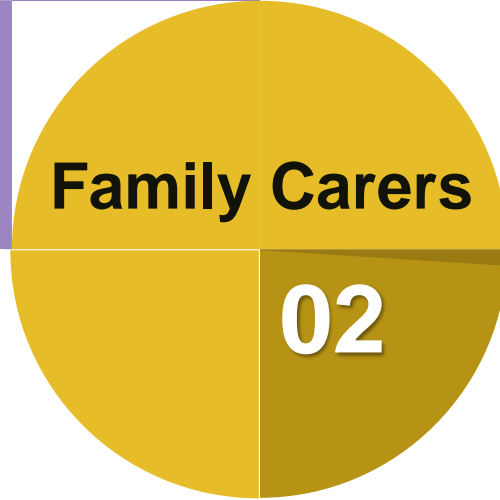
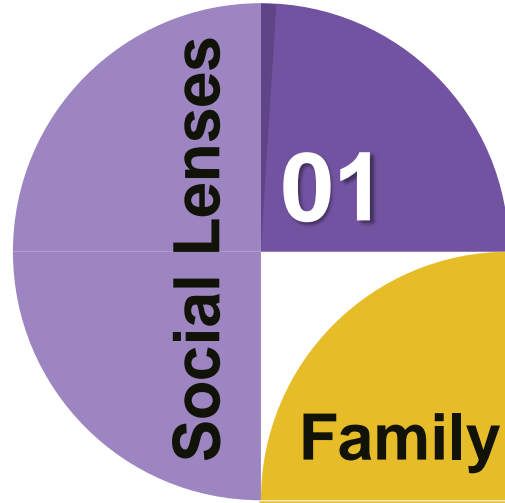


# Dementia: a 'social (care)' lens



- x Give its reach and significance to the lives and wellbeing of many people with dementia, especially in its more advanced stages, there is a strong case for less investment in medicine and more investment in social care and social work
- x **Key improvements would include:**
  - x investment in the pay and conditions of home care and care home staff
  - x prioritisation of the issues that matter to older people
  - x commissioning models that facilitate sustainability
  - x a career pathway for care staff that rewards retention, skills and 'craft knowledge'







# Carers: (Some) Key Facts

- × **Approx. 10.5m carers in the UK: 1 in 5 adults**
  - × **An *additional* 4.5m people became 'new' carers during the pandemic**
- × **Growing in number as a consequence of three intersecting issues: growth in the number of adults with complex comorbid conditions; promotion of 'family care' as 'best'; extension of community based living at (almost) all costs**
- × **1.4 million people provide over 50 hours of care pw; many more carers doing more - & more complex, often quasi medical, care tasks than 10 yrs ago**
- × **A third of all carers are older (60+): number of carers aged *85 and over* has risen by 130% in last ten years to over 90k (mainly spouses)**
- × **5m people in the UK are juggling caring responsibilities with paid work: 1 in 7 members of the workforce (Milne & Larkin, 2023)**

# Policy & Carers: some tensions....

Policy makers have an ambivalent relationship with family carers:

- Need carers to continue caring *but* acknowledge a duty to protect them from harm e.g. preventable ill health, leaving paid work prematurely, falling into poverty
- Benefits of *family care* are strongly promoted in policy discourse: emphasis on keeping an older person at home 'where they are naturally best placed'
  - Tensions between this aim & meeting carers' needs
- Also tension between 'free at the point of access' NHS services & means tested publicly funded social care, eg
  - £9bn pa is spent by people with dementia & families on social care

# Carers & austerity: some additional tensions

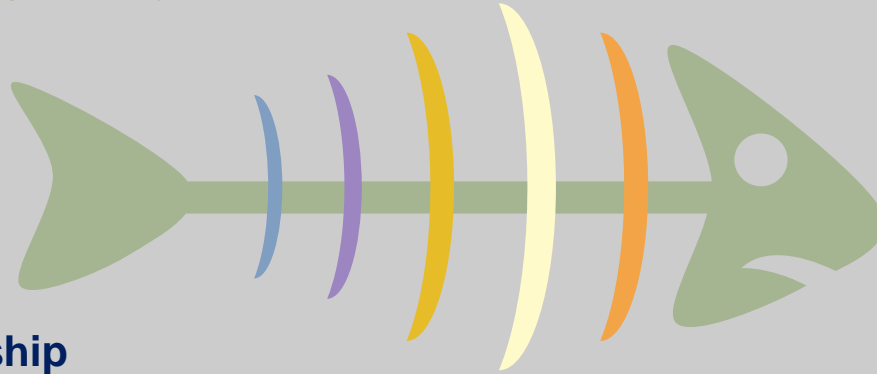
- × **Savage cuts to local authority budgets - in a socio-demographic context of rising demand for care & support - have resulted in **tighter access to publicly funded services****
- × **Despite UK's *Care Act* focus on the importance of supporting carers cuts to have eroded their access to assessments of need and support:**
  - × **Only 10% of carers receive an 'assessment of need'; number in receipt of publicly funded care care is failing - reduction is amplified by Covid**
- × **Far more is also expected to carers now: they care for longer hours and do more complex tasks: supporting people with more challenging conditions too**
- × **Manthorpe and Iliffe (2016) suggest that there is a cruel, rather dark, side to the increased expectations of carers, that *'... the effects of poorly resourced care (services) become framed as a moral failure on the part of family carers who may be accused of being abusive or neglectful of the person they care for'***



# Something fishy about terminology....

Policy documents act as  
'vehicles of normative  
paradigms' (Sevenhuijsen, 2004)

Carers are conceptualised (inevitably?) in  
this discourse as 'heroic' & competent -  
woven around concepts of love, duty,  
obligation & reciprocity



Care relationship  
presented as positive &  
benign not complex,  
nuanced or damaging

Care constructed as 'a set of  
instrumental tasks' not as a nuanced  
emotional lived experience



# How are carers conceptualised by services & professionals?

In the 1990s Twigg & Atkin (1994) argued that professionals working with families of those with 'care & support needs' tend to adopt one of four (implicit) models:

- *Carers as resources: aim of intervention is to 'support' the carer to continue caring*
- *Carers as co-workers: services complement the carer's role*
- *Carers as co-clients: carers have a right to a service in their own right, services relieve them & enhance their wellbeing (see Care Act 2014)*
- *Superseded carers: services support the service user to the extent the carer's input is no longer needed*

Carers as 'experts' is a more recent (additional) construct & one that resonates both the neo-liberal notion of the 'care consumer' & the principles of citizenship

- But... it is notable that the notion of 'expert' carer is having expertise in the care needs of the patient *not* on the experience of being a carer: *nor* 'user in own right' as envisioned by the 2014 Care Act

# Evidence from research

- A study of primary care staff's views of carers of people living with dementia identified a clear conceptualisation of 'carers as co-workers' (Manthorpe et al, 2003):
  - Key role re medication management eg supervising taking of meds, monitoring side effects, helping with patient compliance
  - Carers also alerted professionals to changes in the person living with dementia
- More recent research suggests that carers feel they are regarded - & treated - by professionals as 'free resources' & that the primary function of services is to keep them 'doing caring' - physical care tasks esp - regardless of how they are managing or their own wishes & needs (Manthorpe and Iiffe, 2017)
- Reinforced by evidence that carers are routinely excluded from decisions about their relative's care/care package: also their input is taken account of *before* services are allocated ie services 'substitute' for the carer (Carey, 2021)



# From resources to unpaid workers?

- Offering family carers 'training' to do increasingly complex tasks is emblematic of their 'stealthily growing role' in care provision
- Are we *transferring risk & responsibility* for arranging & providing care from professionals to carers?
  - Evidence suggests that this transfer is placing new emotional demands on carers: Clarke et al (2006) refer to this as '*the devolution of stress*'
  - Managing complex care tasks & making key decisions (e.g. care home admission) is physically challenging & often emotional
  - These can have an impact on health and well being e.g. increased stress & anxiety: especially pronounced for older carers (Baxter & Glendinning, 2013)
- Should professionals be doing this? Is it right? Safe? Does it take account of the carer's age, health, wishes? Are there safeguarding issues? Are there any *limitations* to the caring role?

*The nurse said “you will need to give him his drugs [strong opioids] when I am not here: I’ll show you what to do .... you will have to be ‘me’ when I am not here” (Milligan, 2010)*

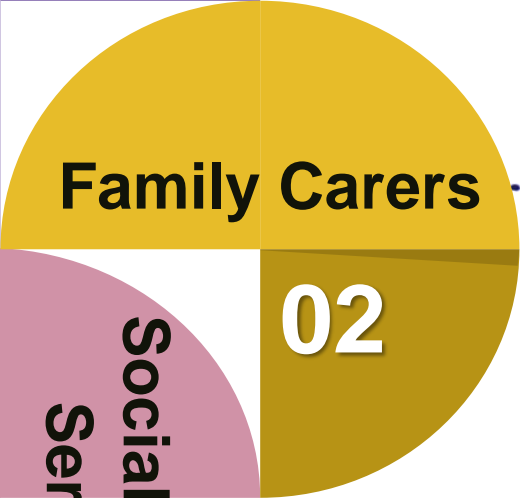


# What is important to recognise

- **Emphasis on ‘identifying carers’ ignores the fact that many ‘carers’ do not recognise their role as that of ‘carer’:**
  - **Concerned that the ‘carer’ identity will subsume their identity as partner, parent or daughter**
  - **Wish to protect the cared for person from being viewed as a ‘burden’**
- **Care is an intrinsic dimension of a familial relationship; reflects mutuality, love, obligation: being a carer is an extension of the relationship & an emotional journey not (just) a set of activities or tasks (Molyneaux et al., 2010)**
- **Practice models tend to ignore the relational (often long term) nature of care: support is not focused on the relationship or dyad but on the individual ‘patient’ and/or ‘carer’ (Rand et al., in press)**
- **This not only fails to reflect the reality for most carers but ignores co-caring e.g. between older spouses**







# Demands on the care and support system

Three-quarters of people aged 65 will need care and support in their later years



19 per cent of men  
and 34 per cent of  
women will need  
residential care

48 per cent of men  
and 51 per cent of  
women will need  
domiciliary care only

33 per cent of men  
and 15 per cent of  
women will never  
need formal care



Older people are the  
key users of hospital  
care - 60% of acute  
admissions, 65% of bed  
days and 70% of  
emergency  
readmissions.

72% of recipients of  
social care services are  
older people,  
accounting for 50% of  
expenditure on adult  
social care.

# Who uses publicly funded social care?

- Increasingly polarised groups of older service users:
  - Those who are obliged to rely on increasingly tightly rationed publicly funded care (poorer, more dependent, fewer resources), vs
  - Those who self fund and buy their own care (more independent, greater choice, more resources)
- Stigma attached to relying on the 'state' for social care support: profile of the population who see a social worker
- Scourfield (2007) noted: the reason why the public sector first emerged was to ensure that people who required support could have it provided in a *'secure and dignified manner, being neither reliant on the quirks of the family or the vagaries of the market'*



# What older people value about social care & social work

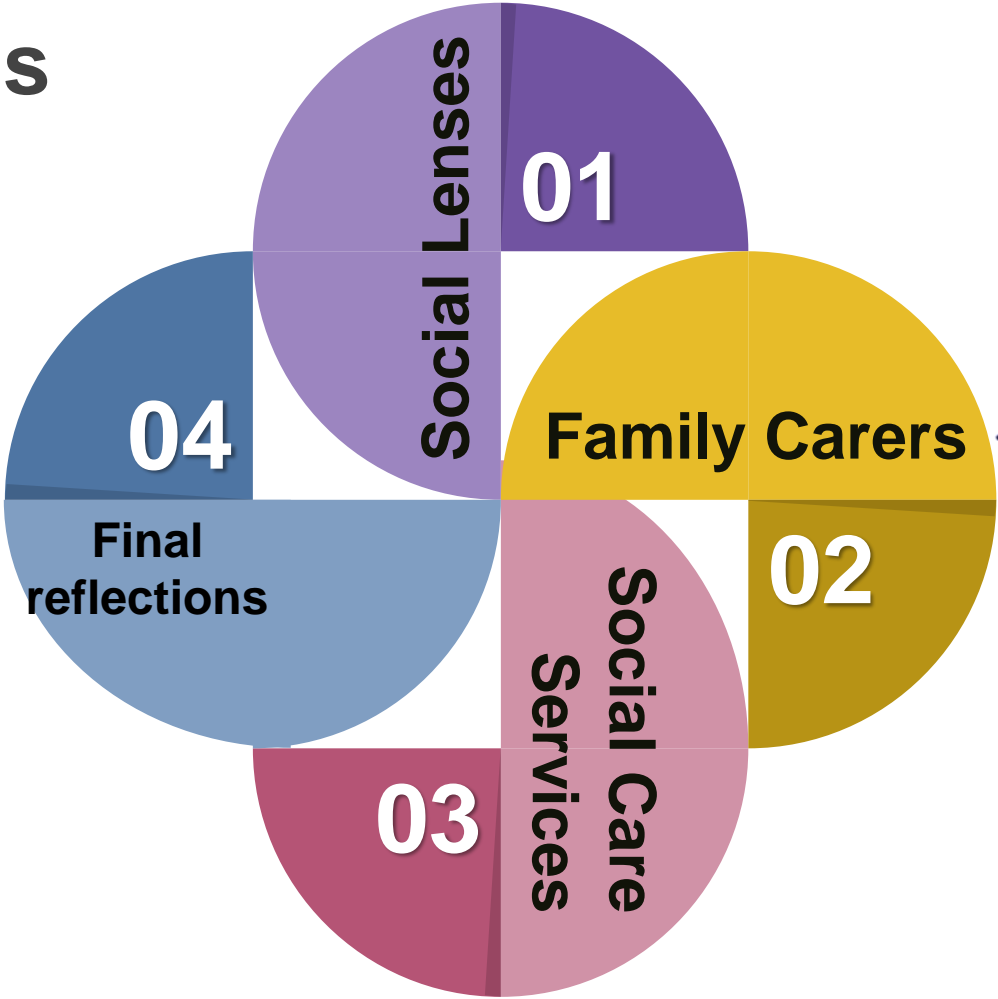
- × A practice that prioritises the relational dimension of care; respect & engagement with decision-making is highly valued (de Sao Jose, 16)
- × The social work *process* is an important to older people as *outcomes* (Ray et al., 2015; Willis et al., 2022)
- × Emphasis on a relational lens to assessment & appreciation of ill health, including dementia, as a complex, nuanced lived experience (Grenier, 2012)
- × Good quality assessment & personalised packages of care are much more likely in contexts where the '*older person's - and their carer's - perspectives and priorities are responded to*' (Ray & Phillips, 2012)
- × Users value time, having the same worker to relate to & the development of a trust relationship (Milne, 2020)

# *Strengths-based practice: some promise?*

- *'A collaborative process between the person supported by services & those supporting them, allowing them to work together to determine an outcome that draws on the person's strengths & assets. As such, it concerns itself principally with the quality of the relationship that develops between those providing support & those being supported, as well as the elements that the person seeking support brings to the process'* (Social Care Institute for Excellence, 2015)
- *Relationships are consistently identified as 'key to achieving outcomes, namely maximising user quality of life & facilitating their ability to participate in activities they enjoy & are good at'* (Caiels et al, 2021, p415)



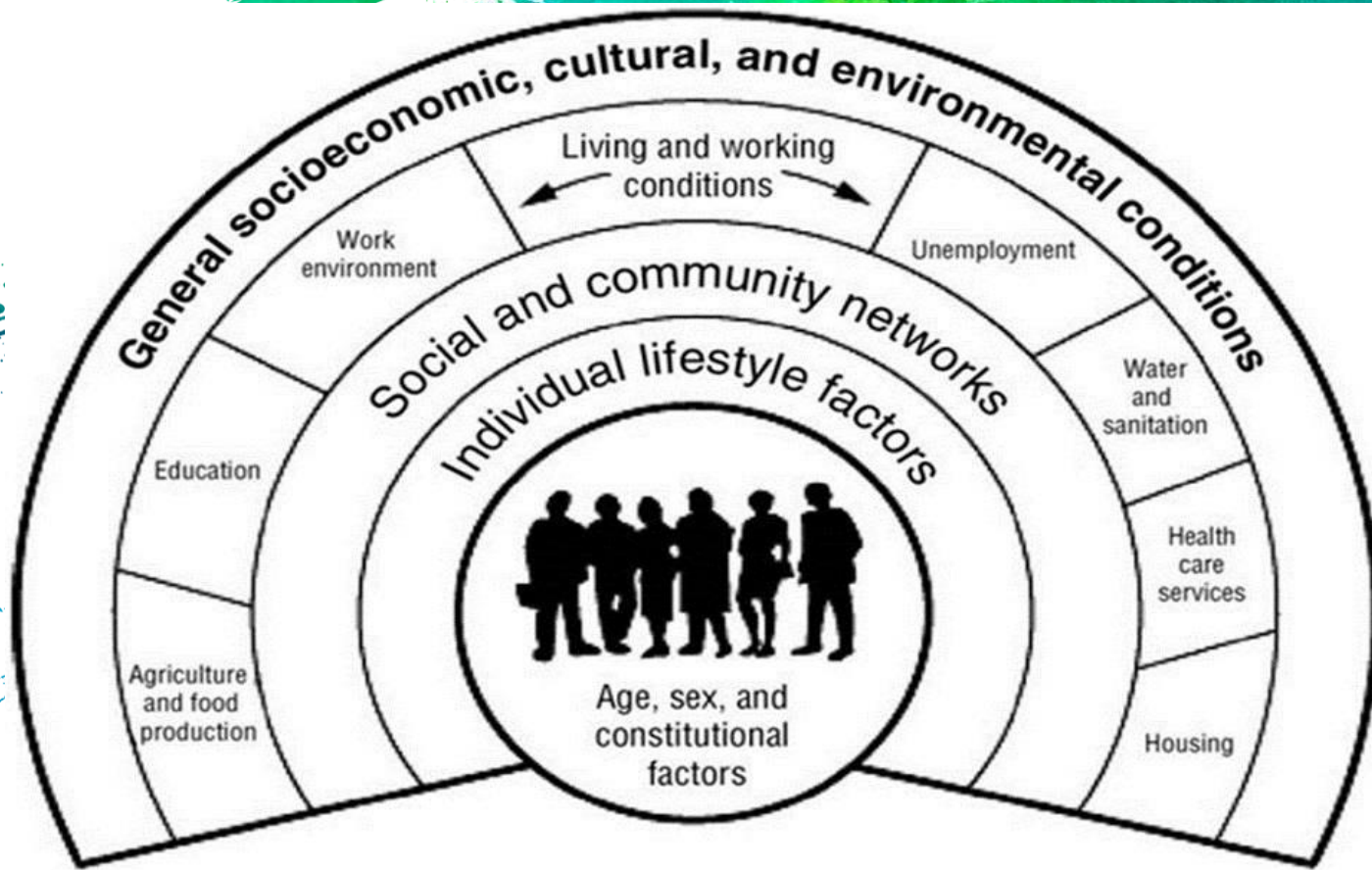
# Aims



# The 'social lens': some final reflections

- The social lens challenges 'lazy' assumptions about links between 'health & old age'; helps us think about the role of the lifecourse and inequalities in influencing health outcomes
- Helps us to engage with the user - and carer's - lived experience, perspectives, relationship & what matters to them as individuals & a dyad
- (Re)conceptualises caring in a different way disrupting the public & policy narrative about the role of the family and what is expected of carers
  - Invest in support for family carers that recognises and respects their role but at the same time accepts that care is a shared responsibility with public services
- Highlights the critical importance of social care *services and staff* to the lives & wellbeing of many older people with care & support needs & their carers:
  - We need to be much more ambitious in relationship to social care and reimagine its transformative potential: it is not just about money!
    - See *Social Care Futures*: <https://socialcarefuture.blog/>

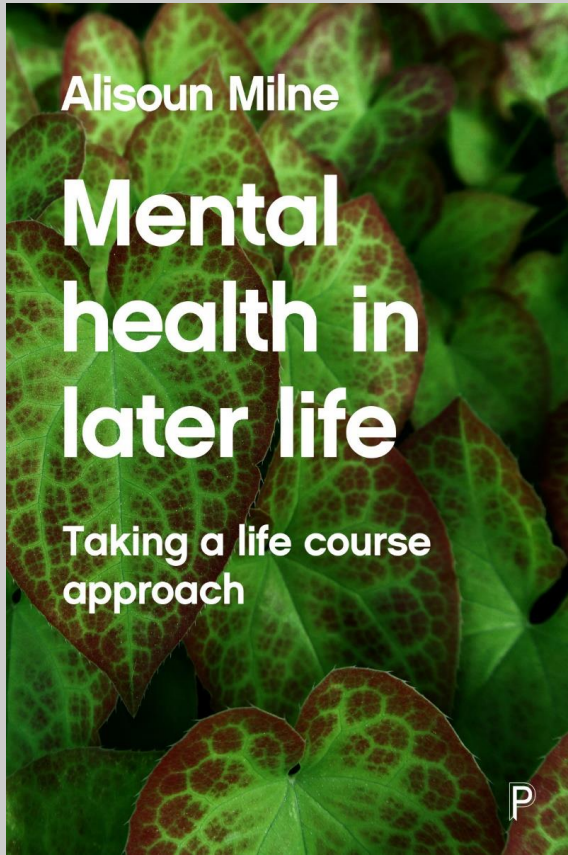
# Social Model of Health (Dahlgren and Whitehead, 1991)



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