

Dementia and the psychological wellbeing of older people and their formal and informal carers

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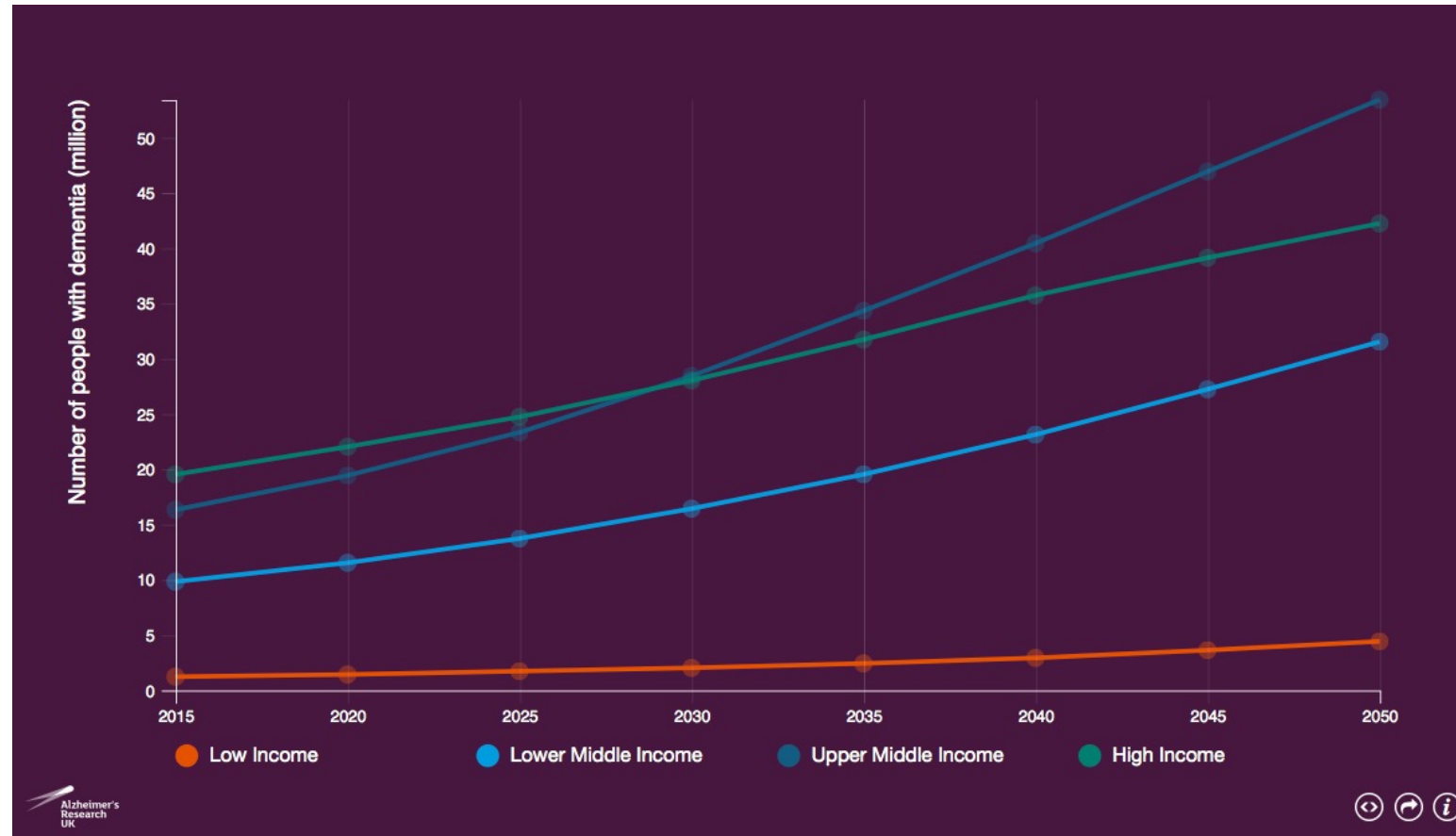
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Dementia in a global context

- ❖ An umbrella term
- ❖ Mainly affect older people
 - ❖ but not a normal part of ageing & can affect younger age groups
- ❖ Estimated to affect 50 million people
 - ❖ Projected to reach 82 M in 2030
 - ❖ Nearly 60% live in LMICs
 - ❖ Under-reporting in many LMICs
- ❖ Considerable physical, psychological, social & economic cost



Policy attention

WHO

- Human rights' approach
- Dementia plan guide

UN Decade of Healthy Ageing & SDGs

Economic & societal cost

Impact on the individual and family
(informal carers)

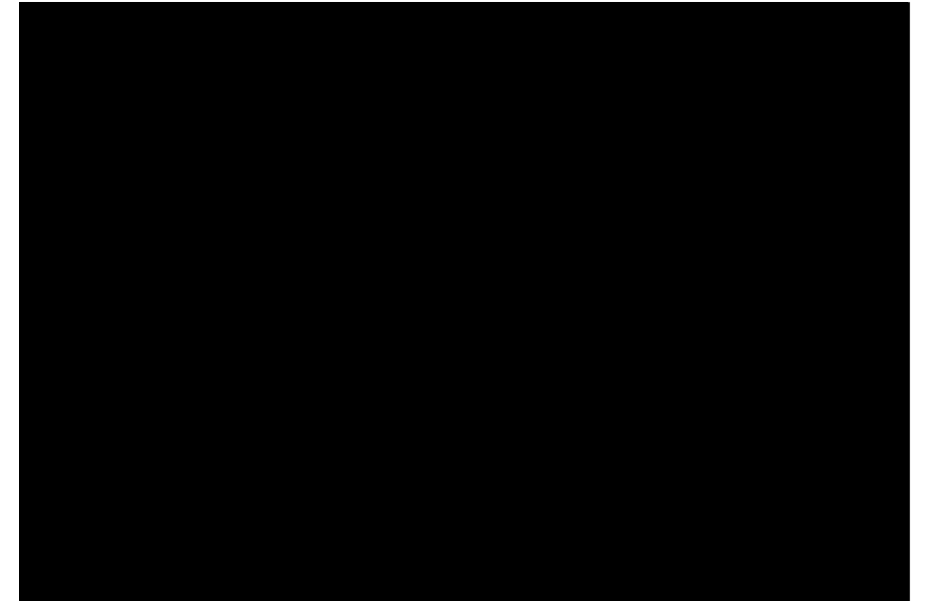
Less attention on the paid workforce



- Pre-existing & new perceptions
- Definitional challenges: what does 'ageism' mean in different contexts and settings?
 - Benevolent and hostile elements
- Operates at different levels: cognition, emotional & actions
- Different components: stereotyping; prejudice and discrimination
- Intersectionality: age, disability, gender, race etc.



- The formal & informal spheres of care
- Workforce training & development
- LTC working conditions and workers' wellbeing
 - Relationships and emotional work; personal & professional boundaries
- Recruitment, retention & sustainability
- Supporting informal carers
 - Care burden
- Self-care
 - AI & Assistive technology
- Care models and preferences



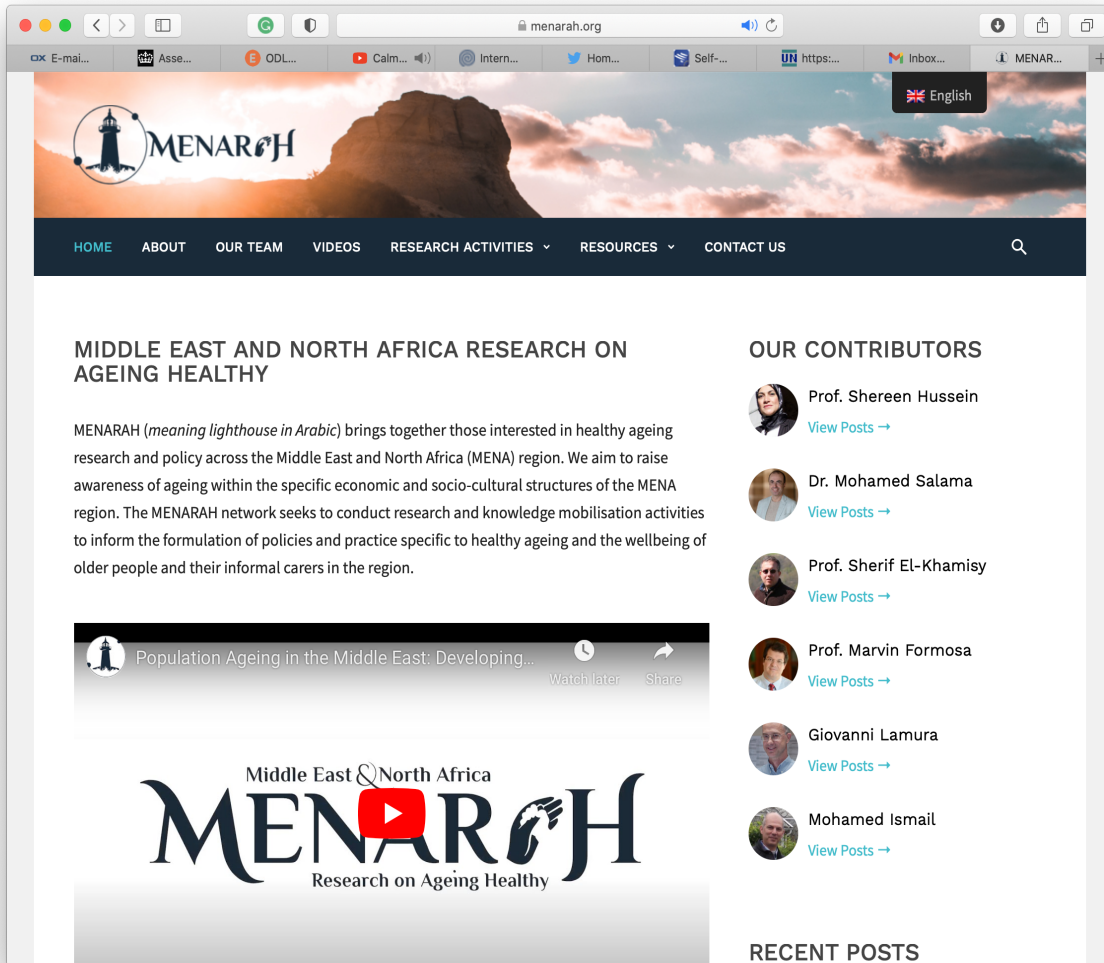
- Universal health coverage remains an aspiration
- LTC is in a policy blind-spot, for many reasons
- Reliance on families (traditional hubs of care)
 - Within a context of dynamic changes in family structures, living arrangements ...
- Environment & infrastructures
- Some recent national, regional and global policy attention
 - Narratives of intergenerational solidarity, families & ageing in place
- Limited LTC services
 - Primarily community based, NGOs and informal arrangements
- Lack of acknowledgment of caring burdens (provided mainly by women)
- Opportunities: population dividends & labour supply

Wellbeing & inequalities

Strengthening responses to dementia in developing countries (STRiDE)

- Theory of Change (ToC)
- Dementia awareness & Stigma
- The cost of unpaid care
- Cost & data
- Models of Care
- Training & Building capacity
- Accessible evidence
- Impact, Knowledge exchange & engagement

The Middle East and North Africa Research on Ageing Healthy (MENARAH) Network



- Focuses on healthy ageing including brain health & dementia
- A network of researchers, NGOs, policymakers and practice professionals
- Aims to
 - ❖ Evidence generation
 - ❖ Knowledge mobilisation
 - ❖ Raising awareness & engagement
 - ❖ Inform policy & practice development
 - ❖ LTC, dementia care & UHC

Developing Practical Online Tools

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Our Elder's Health صحة أهلينا 16 June 2020

أهلاً ومرحباً بكم جميعاً في صفحتنا "صحة أهلينا" 😊👍
 رعاية أهلينا والإهتمام بهم وبصحتهم من أهم وأعظم المهام والتي تعتبر جزء رئيسي من مسؤولياتنا وبنقى مهتمين إزاي نحافظ ونعتني بصحتهم وسعادتهم وراحتهم النفسية على أد ما نقدر بس أحياناً بنواجه صعوبات وبنبقى مش قادرين نحدد إيه الأفضل ليهم. يعني عايزين نخلي حياتهم مريحة وسهلة وهما بيكبروا في السن بس في نفس الوقت بيكون مهم جداً ليهم النشاط والحركة وإتنا نهيا لهم الفرص إنهم يقضوا وقت مع العائلة وتكون ليهم أنشطة وحياة إجتماعية لطيفة

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Joint CGCC & CGMH seminar- @DrShereeHussein

The impact of dementia

Context and broader health systems

- ❖ Fragilities of care systems
- (Un)availability of dementia-specific formal support
- ❖ Intersectionality of gender, class & socio-economic status

Unbalanced care burden
Support mechanisms

Societal norms

- ❖ Stigma
- ❖ Public awareness & attitudes

Individual's experience

Perceptions of ageing in general & dementia in particular

Differentials by societal & individual factors

Variations in health and wellbeing at older age is not random

Impact on individuals and families

Managing the disease and its consequences

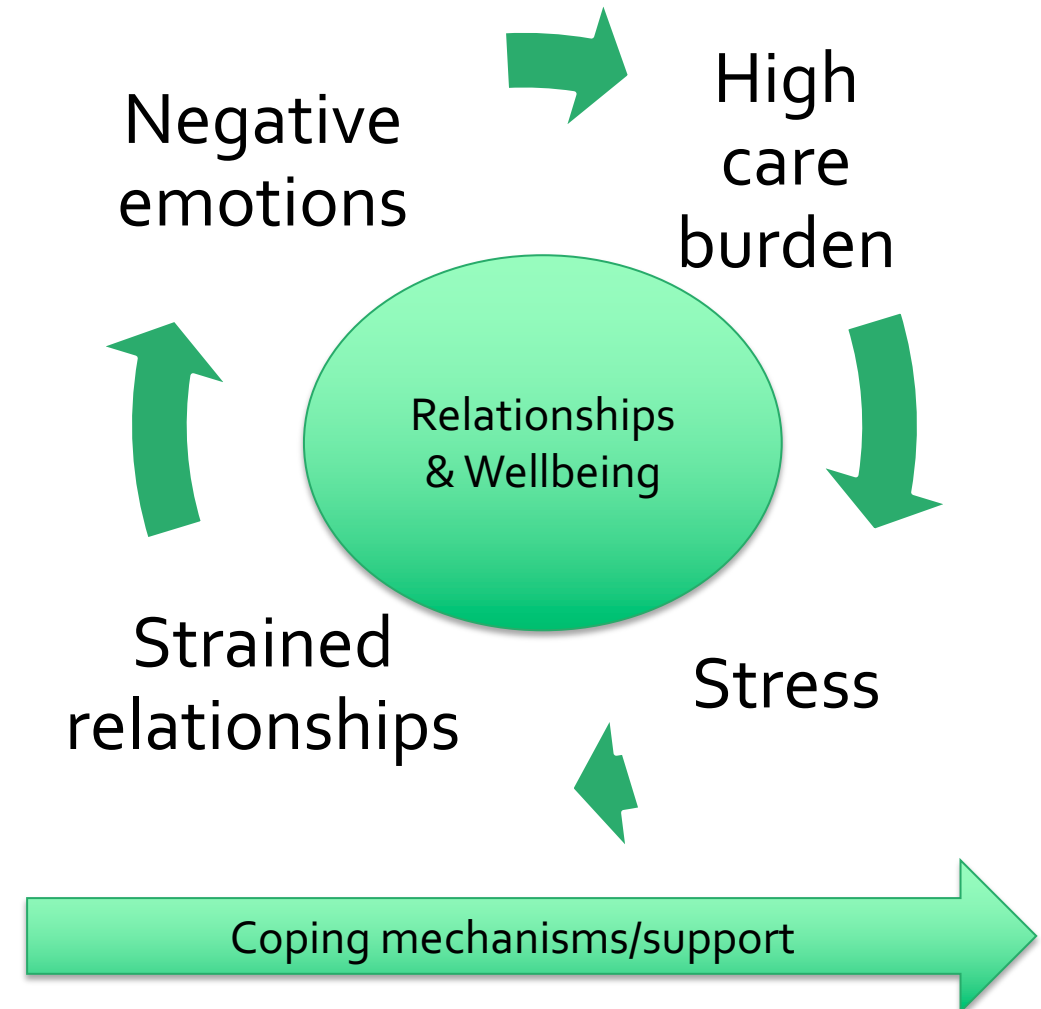
- ❖ Access to & trust in medical support

Managing negative views & stigma

- ❖ Cultural context
- ❖ (lack of) control
- ❖ Doing it 'alone'
 - ❖ Shame and embarrassment
 - ❖ Relating & interacting with others
- ❖ Self-stigma

Power relationships

- ❖ Abuse & neglect



Medical and LTC pathways

- ❖ Multi disciplinary approach & coordination

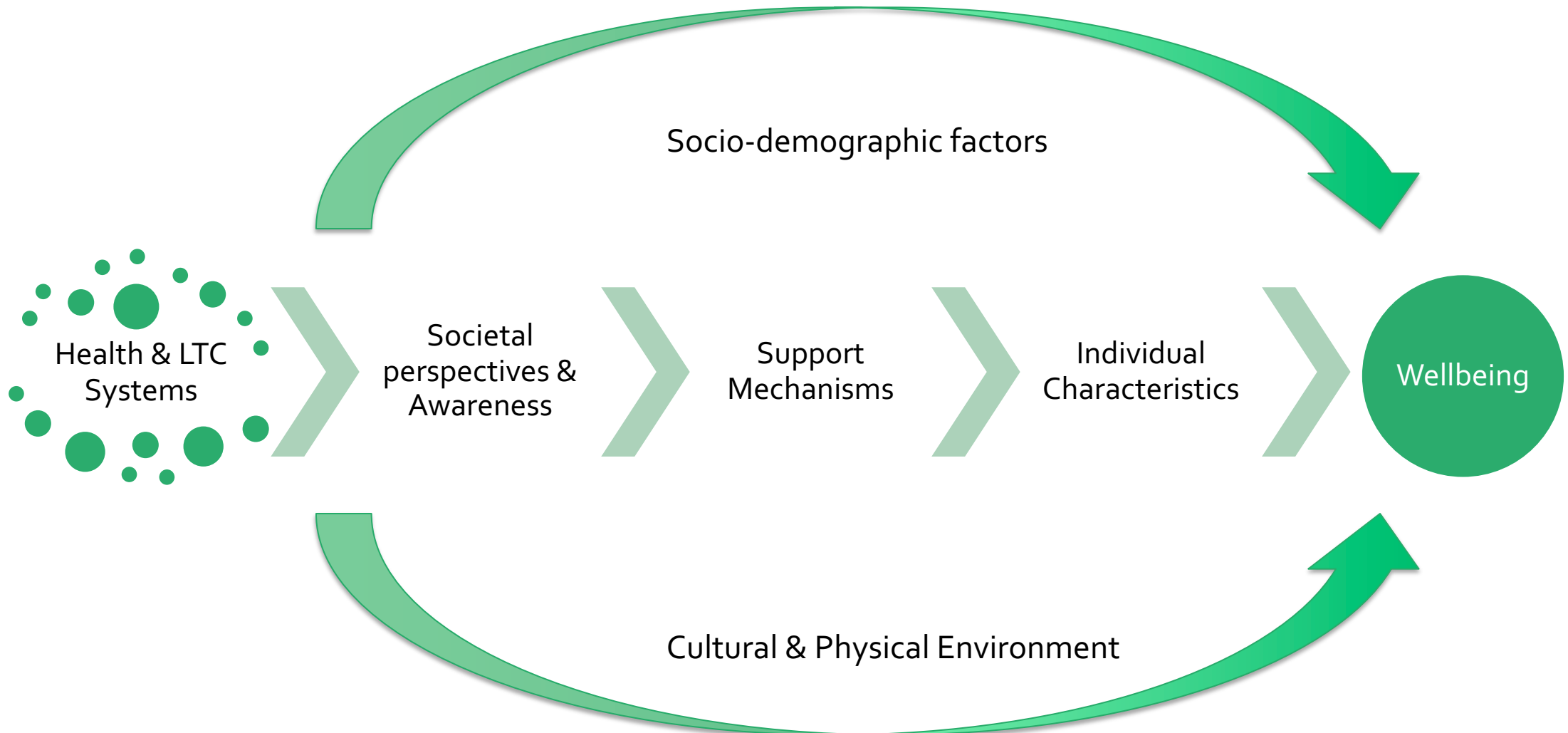
The role of traditional healers (LMIC)

- ❖ Should be a recognized element of care pathways
- ❖ Community support

Public awareness & Media

Importance of building trust & good relationships

Determinants of dementia-related wellbeing



- Cultural-sensitive and context-specific policy & strategic direction
 - Ensuring all stakeholders perspectives
- Recognising the impact of stigma in accessing care and wellbeing of individuals and their family carers
 - Public perception and awareness raising
- The burden of dementia care is multi-dimensional
 - Financial, emotional, social exclusion
- Intersectionality
 - Gender, social class, poverty
- Training for formal and informal carers
- Ageism, abuse & neglect

Thank you for Listening

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