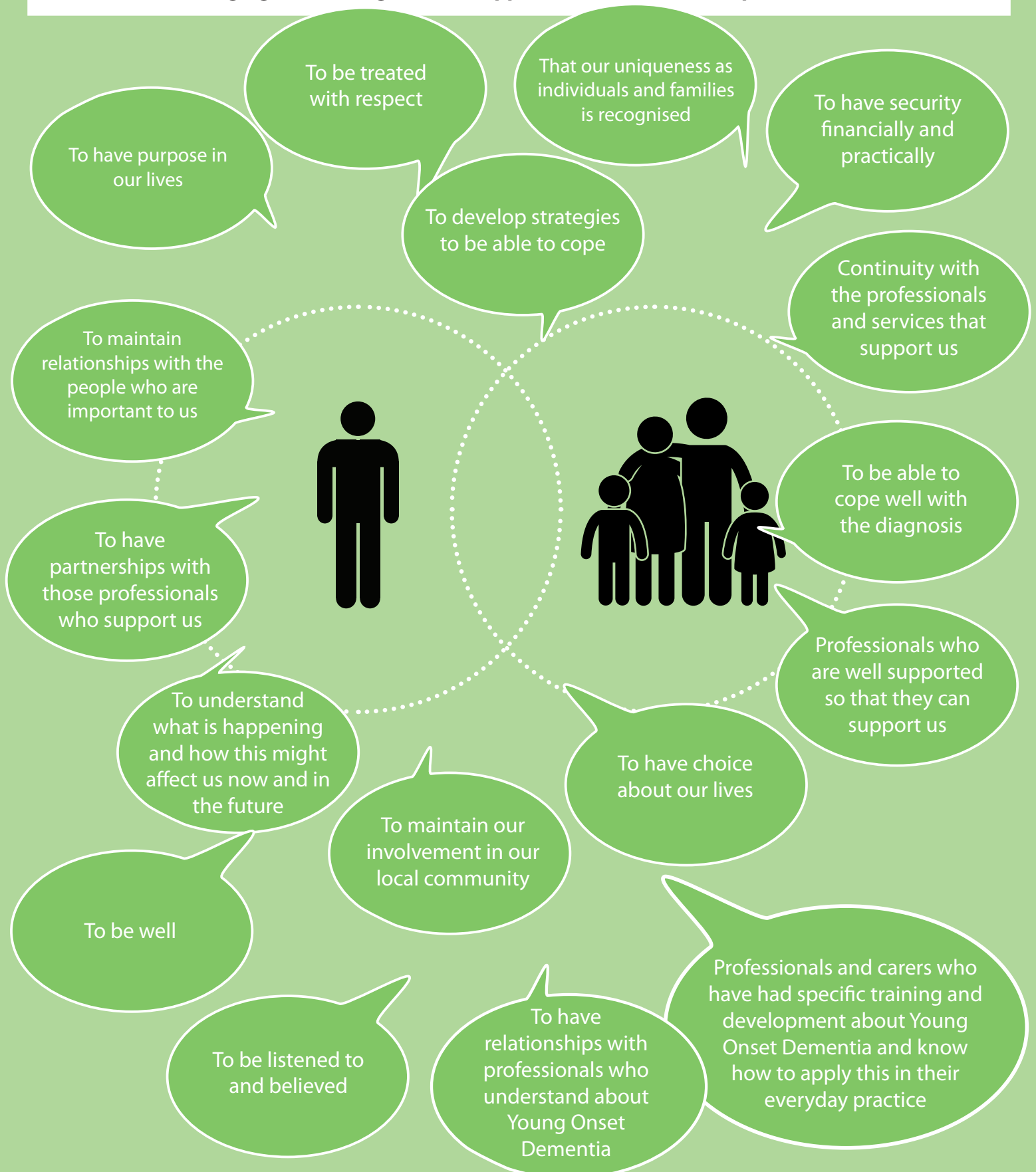
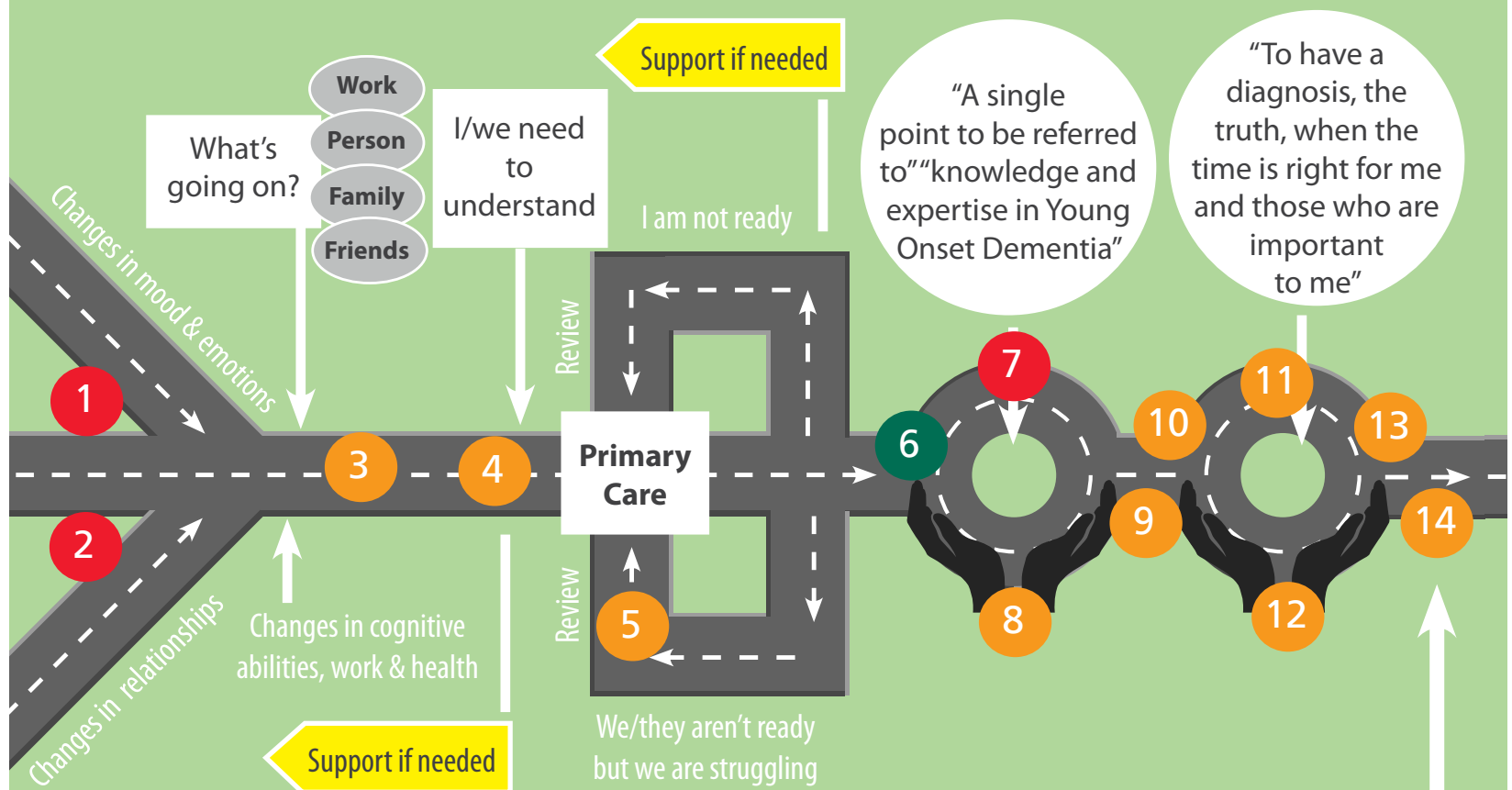


VALUES AND BELIEFS INFORMING SERVICES FOR YOUNGER PEOPLE WITH DEMENTIA AND THEIR FAMILIES

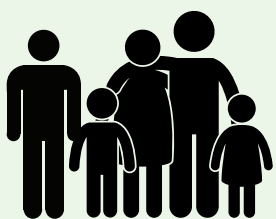
We may have had a difficult journey to get to this point and we may have shared and differing perspectives on what we need as a family and as individuals, but underpinning this we believe that the following rights should guide the support and services developed for and with us:



THE EARLY EXPERIENCE OF SYMPTOMS LEADING UP TO A DIAGNOSIS AND POST DIAGNOSTIC SUPPORT



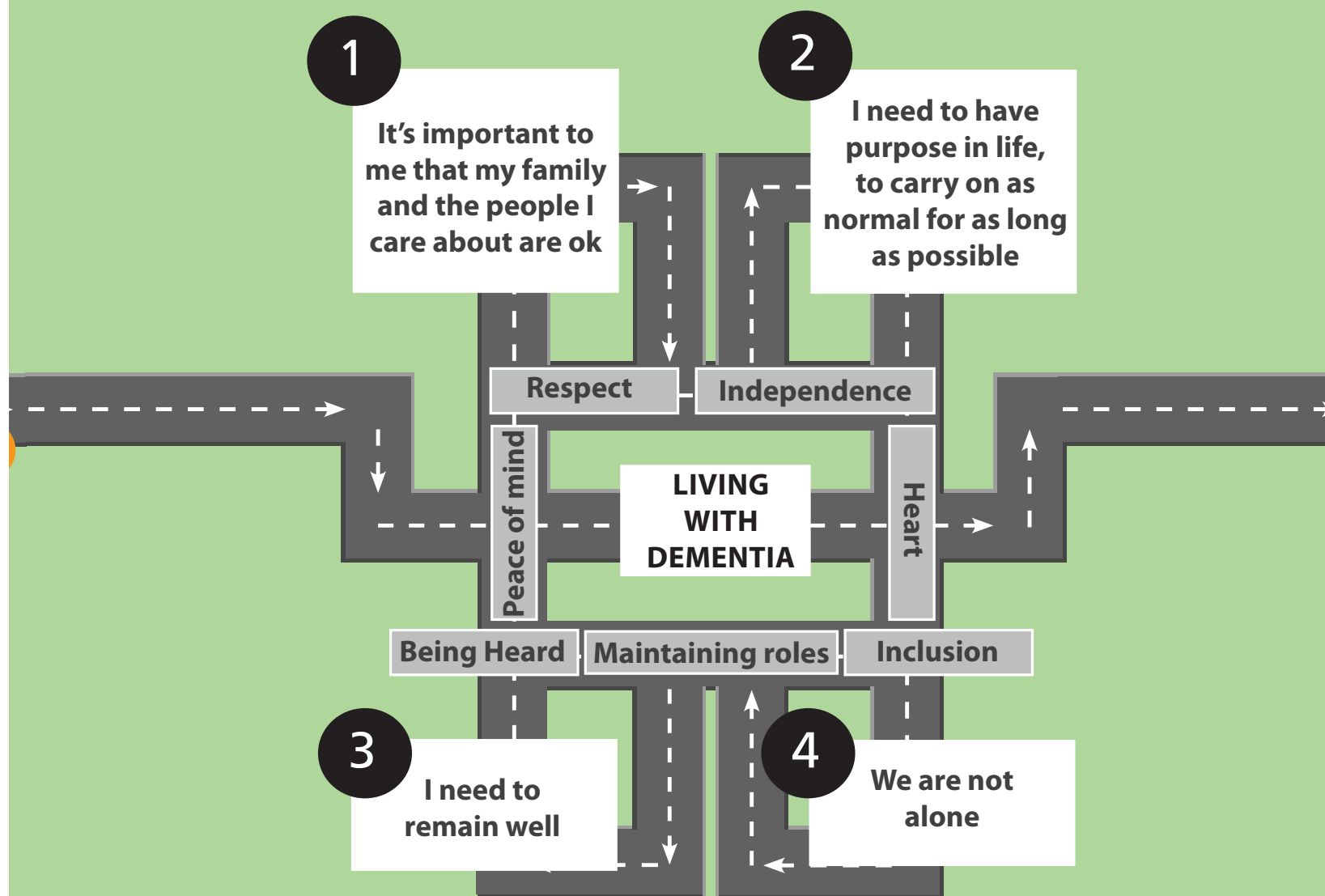
- | | | | |
|--|--|--|------------------------------|
| 1 Noticing changes | 5 Knowledge and understanding of dementia at a younger age and what to do. | 8 To be held and supported through the process of assessment | 11 Knowledge of YOD |
| 2 Complex and unusual changes | 6 EIDS Works | 9 Support to cope with the news | 12 To know where to get help |
| 3 Public and organisational awareness of dementia at a younger age | 7 Currently referrals go to many other sources, danger of getting lost in the system | 10 Use of euphemisms or jargon | 13 To understand |
| 4 Recognition at an early and timely point | | | 14 Information |



To begin the process of living my life as I wish to:

- To talk about the diagnosis and what it means
- To have purpose
- To be independent
- To feel supported
- To maintain relationships
- Financial security
- Inclusion

- Planning for the future
- To understand and learn how to cope with the challenges
- That my family are supported and their needs are recognised and responded to including
 - o Adult Children
 - o Spouse/ Partner
 - o Children and Young People
 - o Other family/ significant others



1

- Time apart and time together
- Information and help to understand and manage the challenges young onset dementia brings
- Accessible help that is local to me/ us
- Help to manage family needs
- Support for the younger person with dementia so that they are happy and we can have time to ourselves
- Support for my family to cope with the impact of dementia
- Support for children and young people to cope with the impact of dementia

2

- To stay in work for as long as I can
- To do voluntary work
- To engage in local activities that I enjoy
- To continue to drive for as long as I can
- To have assisted transport when I can't drive
- To have support to help me to access the activities I enjoy
- Financial security

3

- I/ we need information that is tailored to my/our needs and easily accessible when I/ we need it
- I/we need information that is specifically tailored to the less common forms of dementia
- I/ we need to understand how to manage the challenges that my diagnosis brings for me/ us
- I/ we need to be able to access technology that can help me to remain independent
- I need to remain well for as long as possible

4

- Opportunities to share with others in a similar position and learn from each other
- Opportunities for fun with others
- Continuity of support



- 1**
- I have regular planned reviews with my family doctor
 - I have access to specialist help where this is needed, e.g. with swallowing and dietary needs, dentistry or continence services

- Information about these specialist services are accessible and available
- These services understand about young onset dementia and how they need to support me
- Where I need admission to hospital, information about my care and routines are listened to, to care for me
- My family/ supporters are able to be involved in my care while I am in hospital

- 2**
- Clear information and support to understand how to use a personal budget
 - Support to identify what is needed when we are self-funding
 - Clear information about services that provide support for younger people with dementia
 - A middle ground between managing personal budgets and local authority managed care

- 3**
- Accessible and tailored information and education about dementia
 - Information and advice about medication
 - Information about what services are offered by different care providers
 - Information about CHC funding

- 4**
- We know who the professionals and services are, that are involved in our care
 - We know who to contact to discuss concerns and obtain support

- Where we need this, we have a familiar team of people supporting us
- These professionals understand and know how to support my needs as a younger person with dementia
- Information about my needs and who I am as a person are used by staff to understand me
- Where transfers occur, those involved in my care handover and ensure that the new service is fully informed

- 5**
- Support that allows us as individuals and a family to address the emotional experience of coping with and living with dementia at a younger age
 - Realistic expectations of children and young people who have a parent or significant person in their lives with dementia

- Opportunities to meet with others who are in a similar position
- A buddy who understands our experiences when we don't wish to meet in groups
- Support to enable us to maintain our own physical and emotional wellbeing

- 6**
- Care home provision that is provided in Worcestershire
 - Specialises in providing care for younger people with dementia
 - Includes and involves my family as partners in care
 - Is able to meet my needs to remain active
 - Staff who are knowledgeable and understand how to support me
 - Provide respite care
 - Provide information concerning what they offer that is clear
 - A family doctor who is linked to the home

- 7**
- Carers who understand how to support a younger person with dementia
 - Carers who are able to take the time to get to know me and provide support that is tailored to my needs

- Carers who understand about less common forms of dementia
- Continuity with carers who have got to know me

- 8**
- Opportunities to share with others in a similar position and learn from each other
 - Opportunities for fun with others
 - Continuity of support

- 9**
- Opportunities for meaningful activity that also meets my need for personal care
 - My family can have time for themselves knowing I am happy and that my needs

- are responded to
- Flexible breaks vouchers can be used for day services

- 10**
- We can plan for the future
 - We have emergency plans

- 11**
- How to get an assessment
 - A proactive response which is timely and prevents crisis
 - All my needs are assessed

- We are informed about the process and timescales
- We have an informed discussion about the results of this assessment
- We understand the choices we have available to us
- We understand the outcomes of assessment
- Our financial circumstances are assessed appropriately
- We have the benefits we are entitled to (red)
- The right services are involved in assessment in a timely manner