

Dementia Workgroup  
Co-Production Workshop 4  
Tuesday 6 February 2018

### **What would be my ideal respite option?**

- Day respite, last minute, 4 hour respite block
- Consistency – respite in same place – day and night options
- Flexible hours in home that works for me – tailored
- Prefer longer planned respite
- Transport: pick-up
- Assisted respite holidays – options
- Holidays with dementia options/group eg kids club
- Home from home
- In home respite that stimulated them
- Planned respite – cottage respite 7 days
- Less stressful in home care 'respite' that's not family – no big hassle to organise

### **How would it contribute to our wellness?**

- It helped me 'the carer'
- It would 'free' me up (removes the 'noose')
- Keep them active and engaged
- Allows me to dream again – individually and as a couple
- Wellness, relax, time out, catch-up with friends, learning – dementia courses, support groups
- Mentally – family ties strengthen
- If ill they are being looked after
- Release me from being trapped – have choices
- Support groups need to relate to your situation
- Preserve carers' sanity

### **How often is the respite needed?**

- Before I lose the plot
- All day respite: 10:00am to 4:00pm, X2 overnights per month
- Overnight X1 per month, time out 4 hours per week, 1 whole day per week (Norman House)
- Could be as often as a few days or a week once a month

### **How could it be implemented?**

- More funding: \$ respite facility and \$ emergency respite
- Model of funding to allow for holiday options
- Transport built into option – no separate charge for transport

### **Discussion Summary**

- Need information for planning
- Memory Clinic is a good connection
- Living with memory loss support group – no longer receiving funding for ongoing group gatherings
- **No one stop shop, only finding things out through word of mouth, trial and error, making lots of phone calls and not getting the answers**
- No recognition from family and friends for the symptoms – it is often down played, or they bury their head in the sand, it's a big issue to face up to

- **Denial is terrifying – acceptance is liberating**
- We need to know where all the information is and who is keeping it up-to-date
- **Create a Resource Guide listing where all the information can be found**
- Doctors don't seem to give information to newly diagnosed patients
- Dementia – gradual onset and a diagnosis is a blessing
- Information can be found at many sites:
  - Carers Gateway: <https://www.carergateway.gov.au/>
  - Carers SA: <https://www.carers-sa.asn.au/>
  - My Aged Care: <https://www.myagedcare.gov.au/>