People living with an Intellectual Disability

People living with an intellectual disability are often marginalised. This has a significant impact on whether the older person feels valued and has a sense of belonging. It is important that the older person is included in all decision-making processes about their care.

Ageing with an intellectual disability

Many people with an intellectual disability have not had opportunities to work and therefore, do not see getting older as a time to rest and take time for self-development. Fulfilling, meaningful activities and building social networks is often what gives the person purpose. It’s important to assist the older person to continue with what they find personally meaningful; this can be listening to music, being out in nature, playing board games or being in the company of friends and family.

- The older person can become discouraged from participating in activities they used to enjoy when they start to notice their physical decline. Try adapting the activities to be their current level, for example you could let them complete an activity sitting rather than standing. If you notice this happening, you could say: I know it’s hard for you right now, but you might feel much better after seeing your friends and doing things you love.
- Identify sources of meaning, purpose and connection. Does the older person have opportunities to practice meditation or relaxation techniques? Does the older person believe in God, or follow a particular faith? You may be able to refer the older person to a spiritual care practitioner who will work with the older person through difficult times.

Institutionalisation and the effects on the older person

The older people in your care now may have been institutionalised because of their disability. When institutionalisation was introduced in Australia, families were given the choice to give up their children to be looked after by the state. Institutionalisation may have a great impact on the older person in your care, on their spirituality and overall wellbeing. Sexual, physical and emotional abuse was a normal occurrence within institutionalised care. Sometimes the abuse came from workers, and resident-to-resident abuse was common.

- A person who has been institutionalised may also have strong feelings of abandonment towards family members, distrust towards workers and a deep fear of other residents.
- It is highly important that the older person in your care feels listened to and believed.
- If you notice the older person in your care expressing fear of being in care, you could say: You are safe here, we are here to care and look after you. You look worried; do you want to tell me about that?
Connections with others
Connections with family and friends can be very complex for the older person in your care. While there are many older people living with an intellectual disability who are greatly supported by family and friends, many more are not.

- Find out more about the older person’s support network. You could say: *Tell me about the people who care about you or Who is important and special to you?*
- The older person needs to feel accepted and respected in a wider community. You could create a buddy system with friendly and willing residents/clients based on similar interests.
- If the older person’s parents have been their primary support and they are now in care or their parents have died, the older person may still be dealing with a lot of grief. It is also common for people with an intellectual disability to be excluded from grieving rituals, even if it is their own parent’s funeral. Listen for cues that they are grieving and ask if the older person would like to speak to a spiritual care practitioner.
- The older person’s siblings may not want to support the older person, or feel they are not well equipped to do so. This can cause a lot of pain for both the siblings as well as the older person. You could speak with the older person’s family to find out how you can support them to be more involved in care giving.
- With time and regular involvement in meaningful activities, the older person may have built a very supportive network. It is important that this can be supported in creative ways if the older person is not well enough to go outside. Assisting the older person to use technology, like an iPad or mobile phone to re-connect with friends can make the older person feel loved and continue to be part of a community. Keep in mind that using images may help to communicate with the older person. *Compic image library* can be used to assist communicating with people with little to no speech, poor literacy and language barriers.
- Creating meaningful connections can be difficult for older people with an intellectual disability, many will see deep friendships or want to care for someone. Using dolls can be useful with some older people and interaction with live animals can be a very positive experience.

Ways you can show you care
There are many ways that an older person with an intellectual disability will show you that they care. Older people with an intellectual disability can be very affectionate towards you if they consider you a friend. One thing that can be quite difficult to address is accepting hugs. The older person may have experienced a lot of rejection in their lives and rejecting their hug outright may remind them of their past. Make sure you know what your organisation expects of you in this situation. Show that you care in a way that feels comfortable to you, like a hand shake or by giving the older person a high five. You could say: *Thank you for the hug, I am not allowed to hug you back, so next time I will put my hand on your shoulder.*

- Use short, straight to the point questions and give one step at a time instructions.
- If you notice the older person looks sad, you could say: *You look very sad today, has something happened? or What can I help you with?*
- Similarly, if you notice the older person looks happy, you could say: *You look happy today! What has put you in such a good mood?*
- Older people need strong and consistent routines to assist them to feel safe.
- Never make assumptions about their capacity, always ask if they can do something for themselves first before offering help. Making an older person with an intellectual disability feel useful can be very meaningful to them.
- Aches and pains can be hard to distinguish between for the older person. This can mean that an injury can be a lot worse than how they have described it. You could ask about pain by using pictures from popular comics and ensure all injuries are investigated and examined well.
- Make a big deal about birthdays and involve other clients/residents.
- Assist the older person to continue with their passions. For example: if the older person has a favourite football team, work with them to display the team’s colours, mascot and posters of team players in their space. If the older person has a favourite actor, you could help the older person get some pictures and ensure that he/she has access to watch their favourite movies.
- If the older person was connected with a faith group but it unable to visit, giving access to faith songs or regular spiritual care visits can help to secure those connections.

For more resources and links to useful reading for your own information on People Living with an Intellectual Disability visit the Meaningful Ageing website Member’s Zone. With thanks to Emma Smith, OC Connections (formerly Oakleigh Centre) and Reverend Andy Calder, Uniting Church Synod of Victoria & Tasmania for their assistance in preparing this Consideration.

---

**Meaningful Ageing Australia (formerly PASCOP)**

**Ph:** (03) 8387 2274  
**Em:** admin@meaningfulageing.org.au  
**Web:** www.meaningfulageing.org.au

**SPPRITUAL CARE considerations series**

**PO Box 2127**  
Royal Melbourne Hospital VIC 3050