



## Self-Assessment

*Informed by discussions and lived experiences shared by Thalidomiders and similar disabilities at the 2026 Thalidomide Society Conference and AGM*

### Introduction

This helpsheet brings together reflections, challenges, and insights shared across multiple AGM workshop groups. It is designed to help you think about your **current independence, future support needs**, and the **practical and emotional factors** that influence daily life.

It is not an assessment of what you *should* be doing; it is a tool to help you understand what is changing, what is working, and what might help you maintain control, dignity, and quality of life.

### 1. Looking Back: How Have Things Changed Over the Past 10 Years?

Many shared that they had not realised how much had changed until they paused to reflect. Common themes included:

- Increased fatigue, aches, and reduced energy
- Tasks taking longer or requiring more planning
- More difficulty with mobility, transfers, and dressing
- Greater reliance on partners, relatives, or friends — often more than realised
- Challenges becoming more noticeable outside the adapted home environment
- Sensory changes (hearing, vision) affecting communication and confidence
- Reduced ability to manage travel, childcare, or physically demanding hobbies

#### Reflection prompt:

Which activities now feel harder, slower, or more draining than they used to?

### 2. Daily Life Today: What's Becoming More Challenging?

Feedback from AGM groups highlighted several areas where people noticed increasing strain:

#### Physical Tasks

- Dressing, especially when alone
- Meal preparation and kitchen tasks
- Lifting, bending, reaching, or carrying
- Managing pain, injuries, or balance
- Household tasks (cleaning, laundry, linen, gardening)

#### Sensory & Communication Challenges

- Hearing deterioration affecting group conversations
- Difficulty with accents, phone systems, or long call waits
- Online services that are not accessible
- Needing quieter environments or alternative communication methods

### **Emotional & Cognitive Load**

- Feeling overwhelmed by admin or decision-making
- Worrying about burdening partners
- Hesitation to ask for help
- Fear of losing control or becoming “lazy” with support

### **Reflection prompt:**

Which tasks drain your energy the most? Which ones do you avoid or delay?

### **3. Support Systems: What Helps You Stay Independent?**

Participants described a wide range of supports that help maintain independence:

#### **Practical Support**

- Cleaners, gardeners, and domestic help
- Personal Assistants (PAs) for daily tasks, hobbies, or community activities
- Technology (speech-to-text, email, text messaging)
- Adapted homes and equipment
- Payroll companies for managing PA employment

#### **Benefits of Having a PA**

- More energy for enjoyable activities
- Reduced strain on partners
- Improved relationships (partner vs. carer roles)
- Greater flexibility and control
- Reduced isolation and increased social participation

#### **Challenges of Having a PA**

- Privacy concerns
- Emotional barriers (guilt, embarrassment)
- Finding the right person
- Admin responsibilities (contracts, tax, insurance)

### **Reflection prompt:**

What support already helps you? What small additions could make life easier?

### **4. Barriers to Accepting Help: What Holds You Back?**

Across groups, several common concerns emerged:

- “I don’t want to lose control.”
- “If I get help, I’ll become lazy.”
- “I manage fine, I don’t need support yet.”
- “I don’t want someone in my home.”
- “My partner helps, we manage.”
- “I don’t want to seem like I’m asking for too much.”

However, many participants realised:

- Partners are also ageing and becoming less able to help
- Independence outside the home is often much lower than inside
- Support can *increase* control, not reduce it
- Help can prevent burnout, pain, and long-term decline
- Support can enable hobbies, social life, and wellbeing

**Reflection prompt:**

What worries you most about accepting support? What might help ease those concerns?

**5. Thinking Ahead: What Might the Next 10 Years Look Like?**

Participants acknowledged that:

- Abilities may decline further
- Support needs may increase
- Planning early reduces stress later
- The “right support at the right time” protects independence
- Living arrangements may need to adapt (e.g., annexes, live-in support)

**Reflection prompt:**

What changes do you expect in the next decade? What would help you stay in control?

**6. Key Questions for Your Self-Assessment**

Use these questions to guide your reflection or discussion with a professional, partner, or PA.

**Question 1**

Looking back over the past 10 years, which activities or aspects of daily life have become more challenging?

**Question 2**

Where could small changes or the right support make life easier while helping you stay in control?

**Question 3**

What concerns or uncertainties make you hesitant about exploring additional support?

**Additional considerations**

“How independent are you *outside* your adapted home, and what help do you need in those environments?”

**7. Key Takeaways from AGM Participants**

- Independence is not all-or-nothing, it changes gradually
- Support can protect dignity, energy, and wellbeing
- Emotional adjustment is part of the process
- Partners’ ageing needs must also be considered
- Accessible communication is essential
- Direct payments and PA employment involve responsibilities, but support exists
- Asking for help is not a failure, it is a strategy for staying independent longer

## 8. Next Steps You May Wish to Explore

- Review domestic and personal support options
- Explore PA support (including payroll services and training)
- Identify tools, adaptations, or technology that could help
- Consider future living arrangements
- Seek accessible communication options from local authorities
- Continue reflecting on your support needs as they evolve