

SMA UK Lived Experience Template: The Casey Commission

Important note: This consultation relates specifically to social care in England. If you live outside of England (including Scotland, Wales, or Northern Ireland), your experiences may not align with this framework.

Target Word Count: 750 words

This is your opportunity to describe what social care means in your life. The things that work, the things that don't and what needs to change.

1. Introduction: About you (approx. 100 words)

- Are you a person living with SMA, a family member, or an unpaid carer?
- Your Current Care Package: Briefly state what support you currently receive (e.g., Direct Payments, agency care, or local authority-managed care). How many hours of care do you currently receive?
- You could write a sentence about what a good life looks like for you. For example, “a good life to me is having enough reliable support to enable me to work and spend time with my friends without having to worry”

2. The Issues: Barriers to Care (approx. 250 words)

This section is about the everyday barriers that make life harder than it should be.

- You could talk about ...
 - A lack of understanding by your local authority about direct payments and how these should enhance your life
 - Lack of specialist training
 - Long waits for reassessments instead of reviews – have you had a change made to your package when there was no identifiable change in needs?
 - A lack of understanding of SMA from social workers. Do they understand your lifestyle and the outcome of having your care refused?
 - Inconsistency between the NHS and your local Council

You don't need to cover everything; a few examples can be really powerful.

3. When It Works Well (approx. 150 words)

It's just as important to explain what good care looks like.

- You could describe ...
 - A long-term PA who understands you and your routine without you having to explain
 - A successful Personal Health Budget or Direct Payment Setup, how does this control improve your quality of life?
 - A workplace which offered flexibility so you could attend a medical appointment
 - A good budget that meets all of your current needs – do you feel your local authority listen and help to offer services to maintain your independence?

4. The Real Impact (approx. 150 words)

Social care isn't just about washing and dressing.

- Explain how it affects:
 - Your ability to work or study
 - Parenting or family life
 - Friendships and relationships
 - Your independence
 - Your physical and mental health

You could also talk about the emotional impact that social care has. For example, the feeling of losing independence if your social care is changed unexpectedly or having to miss out on social activities with friends and family due to a lack of funds in your budget.

5. What Needs to Change (approx. 100 words)

End with one or two clear messages for Baroness Casey and the Commission.

- Example: "We need national guidance for PAs alongside recognition and awareness that complex conditions like SMA require specialist skills and training."
- Example: "Social care should be viewed as enabling my independence, not just covering the basics."
- Example: "We want the flexibility to manage our own support"

Top tips:

- Use "I" statements: The Commission is looking for your personal perspective.
- Be constructively critical: If you mention a bad experience, try to suggest a solution that may have helped.
- Focus on Phase One: The Commission is currently looking for the definition of the problem so emphasize where the current system is failing to meet the ideal "National Care Service". Look at the process you have experienced, what worked well and what could have been done differently?

Easy Read Statement Template

Section 1: About You

- What is your name and where do you live?
- Do you live at home or in supported living?
- What support do you currently receive?
- What does "good care" mean to you?

Section 2: The Current Problems

- Do you feel you have enough hours of care?
- Is it hard to find PAs who understand SMA or how to use your specialist equipment?
- Have you ever felt isolated because of care issues?

- Do carers ever cancel at short notice?
- Have you had to wait a long time for support?
- Do you feel heard by your local authority?

Section 3: What Works Well?

- Has a carer or provider done anything that stands out?
- Have your care hours remained constant and do they meet your needs?
- Have your carers remained unchanged?
- Has your budget stayed the same?
- Did you feel listened to and respected?

Section 4: My Message to the Commission

- If you could change one thing about social care tomorrow, what would it be?

You can write as much or as little as you want (up to 750 words).