MILESTONES: LIFE JOURNEYS WITH SICKLE CELL

A Report on Aging, Wisdom,Sharing & Community Building

Prepared by: Georgia Adebowale, Patient and Public Voice (PPV) Group Coordinator
West London haemoglobinopathy Coordinating Centre (HCC)

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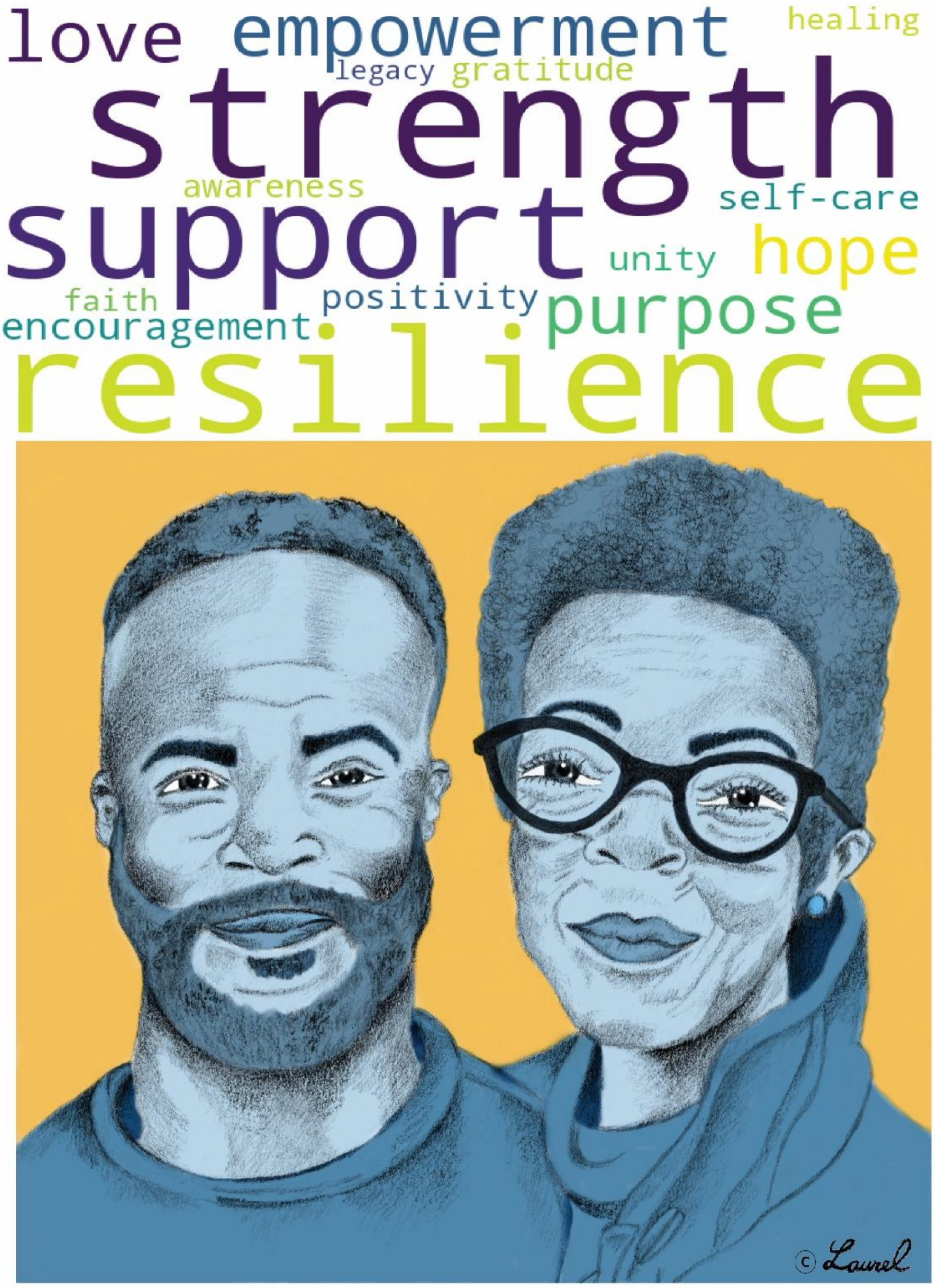


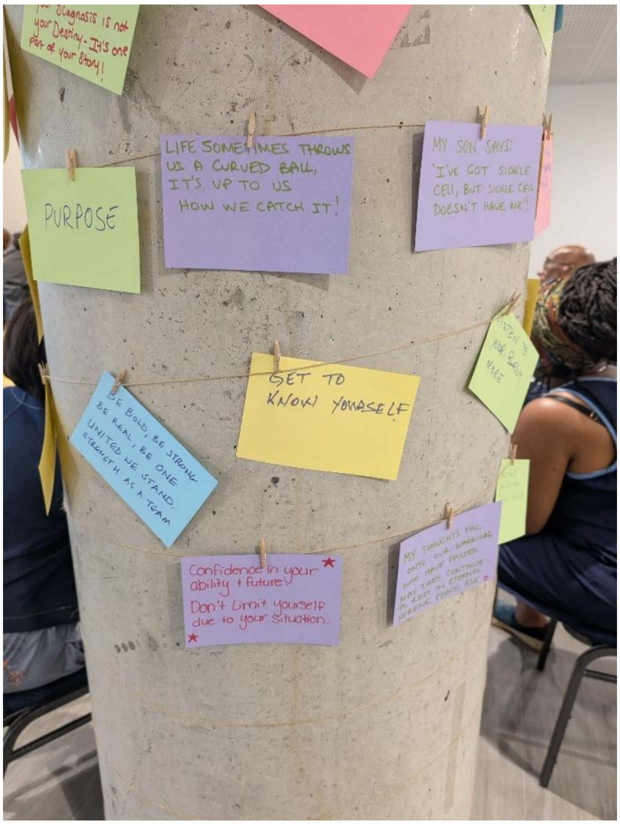
Dedication

Thank you to all who shared their experiences—your voices continue to shape how care and support evolve.

Special thanks to **Chanel Taylor** and **Laurel Brumant-Palmer** for co-designing the event and stepping into facilitation with great care.

Special appreciation to the chairs of the PPV Group **Patrick Ojeer, Sonia Meikle,** and **Ade Sawyerr**, for their dedication throughout the planning process and on the day of the event.

To all working to improve the lives of people with SCD—thank you for your commitment and belief in the power of community.



Summary

This report captures the vision, planning, and insights from *Milestones: Life Journeys with Sickle Cell*, a patient-led event focused on aging with Sickle Cell Disease (SCD). It highlighted the importance of intergenerational dialogue, improved support for older patients, and patient co-design. It aimed to empower younger individuals with the lived wisdom of older patients and help them prepare for the future.

Introduction

The event was created to reflect on the aging journey of individuals living with SCD, particularly those aged 50 and above —not thought possible in the past. The event successfully brought together voices from across the community. Three speakers, two women and one man, shared their life stories through presentations and interviews. They spoke candidly about the challenges and rewards of aging with SCD, their family relationships, and career experiences.

In the afternoon, attendees joined smaller breakout groups of 8 to 10 people for more in-depth conversations. These sessions addressed a gap in services and dialogue around older adults with SCD, shifting the focus beyond medical care to include social, emotional, and practical needs. The smaller group format encouraged more people to speak openly, especially those who might feel hesitant in larger groups. As a result, participants engaged in meaningful and emotionally honest discussions, covering topics such as personal growth, family relationships and grief.

Discussion style

Each breakout group was co-facilitated by members of the PPV group, some of whom have lived experience of the condition. Their empathy and leadership helped build trust and encouraged participation from all attendees. Seeing individuals with lived experience in leadership roles was especially empowering for patients and carers. They allowed conversations to develop organically, leading to a wealth of responses beyond the theme of older age.

Facilitators guided the conversations using four questions developed with input from the PPV group:

- What life milestone are you most proud of reaching, and what or who helped you get there?
- How has your relationship with pain changed over time, and what have you learned?
- How has caring for someone, or receiving care, shaped your view of relationships and strength?
- How has your view of yourself and your condition changed as you’ve aged, and what advice would you give the next generation?

Feedback from Attendees

Milestones received overwhelmingly positive feedback from attendees. All survey respondents were satisfied with the event and expressed strong interest in attending similar events in the future. Participants appreciated the opportunity to share experiential knowledge, with breakout groups enabling vulnerable conversations, laughter, and emotional validation. The life stories shared by speakers were described as empowering and motivational, encouraging openness and connection. Many attendees described the atmosphere as warm and welcoming.

More than three-quarters of attendees were aged 50 and above, with fewer than 20 percent under the age of 50. Importantly, survey responses revealed lower confidence in several key areas related to aging with SCD:

- Financial stability
- Understanding future treatments
- Emotional and mental wellbeing
- Staying connected with others

These insights highlight the need for targeted support and future programming that addresses the evolving needs of older adults.

Discussion

Mental and Emotional Health

This includes managing stress, pain, and emotional challenges, building confidence, and encouraging connection with others who have lived experience of Sickle Cell.

Reflections:

> **Celebrate together:** Staying connected to personal motivations and receiving encouragement were key themes. Participants celebrated milestones like raising children, publishing books, completing courses, and going to university. There was a strong belief that even the little wins matter—and that sharing them with peers who understand the journey makes those achievements feel even more meaningful.
>
> **Faith and resilience**: Spiritual grounding—whether through religion, personal belief, or connection to a higher power—was seen as essential for coping. Participants also highlighted the importance of community support and faith in oneself to stay hopeful and resilient through life's challenges.
>
> **Pain as a teacher:** Pain was reframed as a signal for rest and reflection. Through lived experience, participants developed patience and moderation, learning to recognize stress and set healthy limits. Some stressed a generational shift in pain management, with older adults using fewer painkillers due to limited access in their youth.
>
> **Empathy and advocacy**: Many expressed a desire to help others through their own lived experience. Others who were involved in advocacy found it fulfilling and reflected on how their own emotional challenges could be used to make a difference and feel less alone.

Learnings:

Adult peer support and mentorship: Older adults benefit from sharing wisdom and receiving validation from others, including younger adults, with lived experience. Mentorship can have immense therapeutic value.

From Pain to Purpose: Elders shared how living with pain shaped their emotional resilience over time. Their stories emphasized the importance of creating a legacy, celebrating life's milestones, and shifting the mindset from merely surviving to truly thriving.

Routine mental health screening: Research shows that depression, anxiety, and cognitive decline are common but underdiagnosed in older patients with Sickle Cell. Older patients may not speak openly about these issues—due to stigma, limited language, or a belief that such struggles are simply part of life's ups and downs.

Planning Ahead

Applying life experience helps individuals with SCD make informed choices, prepare for future health and lifestyle changes, and support others through shared learning. Planning for housing, care needs, and independence is essential as people age.

Reflections:

Anticipating health changes: Participants emphasized the value of early planning for co-morbidities and accessible housing. Many wished they had known their risk of complications earlier to take preventative action.

Taking advantage of advancements: There was strong interest in emerging treatments like gene therapy, especially among older participants who missed out on these options in their youth. Many expressed a desire to ensure younger generations are better informed, even if they themselves no longer qualify.

Adapting lifestyle with age: Older adults described becoming more proactive in managing pain, fatigue, and illness. This included practical self-care strategies such as pacing activities, dressing for comfort, avoiding stressors, and using techniques like meditation and breathwork.

Representation matters: Elders reflected on the lack of older role models thriving with SCD which made it difficult to imagine a future when they were younger. The risk is that some may not plan for key aspects of aging, neglecting conversations around pensions, housing, or long-term care for example. One of the guest speakers shared that she opted out of her workplace pension earlier thinking she wouldn't live long but rejoining on her colleagues' advice gave her security when ill health forced early retirement—now she shares this to help others.

Learnings:

Age Specific Support: Develop tailored geriatric reviews for older SCD patients to monitor complications like organ damage, pulmonary hypertension, kidney disease, and silent strokes. Encourage early conversations about future care preferences.

Holistic Support Services: Enhance social prescribing and provide SCD-specific advice on menopause, mobility, nutrition, and exercise. Focus on prevention and delaying chronic complications, while improving understanding of how treatment needs evolve with age.

Housing and Care Coordination: Support patients in adapting homes for mobility and ensure care is integrated across services. Promote accessible housing options and coordinated care planning to maintain independence.

Peer-led education is powerful: Aging brings about a growing sense of advocacy and hope, as well as a desire to help others feel informed and hopeful about what's possible. Elders can offer practical wisdom on navigating systems, managing pain, and emotional coping skills.

Community Support

Supporting individuals with SCD as they age, their families, and carers means fostering strong relationships, building a sense of belonging, and ensuring access to help—especially through peer networks and support groups.

Reflections:

Evolving Roles in Caregiving: Participants reflected on how caregiving responsibilities shift over time. As people with Sickle Cell Disease (SCD) age, many become parents or carers themselves, even while still needing support. Some admitted they hesitate to ask for help, fearing they’ll be seen as a burden. Others shared that they now remind their own carers to rest, showing how care becomes more mutual with age.

The Power of Support Networks: There was strong agreement that reliable support systems are essential, especially during long periods of illness or hospitalisation. One carer shared how staying connected to community activities helped their loved one maintain a sense of identity and joy. Others noted that friendships were key to reintegrating into everyday life after serious illness, some maintained life-long friendships with peers they met through Hospital or groups as young adults.

Confident Parents, Confident Kids: Parents discussed how their emotional wellbeing directly affects their children. Those who felt supported and informed said their children were more confident and optimistic. Others acknowledged that anxiety or guilt could unintentionally impact their children, reinforcing the need for emotional support for the whole family.

Genetic *Counselling*: Support groups offer space for emotional conversations often missing in genetic counselling. Some valued discussing the realities of raising a child with SCD and navigating difficult conversations about reproductive choices with compassion and clarity.

Learnings:

Encourage peer and community connections: Local and national support groups can help reduce isolation and foster long-term relationships. These networks offer valuable emotional and social support, especially during transitions or recovery.

Whole-family support: Emotional wellbeing within families—especially among parents and carers—can influence children’s confidence and resilience. Creating opportunities for families to access emotional support might help strengthen these dynamics.

Acknowledge changing caregiving roles: as individuals with SCD take on caregiving responsibilities themselves, it may be helpful to explore ways to support mutual care and reduce stigma around asking for help.

Support emotionally informed family planning: Facilitate safe spaces for open conversations about genetics, parenting, and long-term planning, with emotional support tailored to both parents and children.

Recommendations

- Raise awareness of aging with SCD among healthcare professionals and the SC community
- Invest in patient-led events and leadership opportunities to create safe, inclusive spaces where individuals feel comfortable sharing difficult experiences and challenges.
- Expand peer mentorship for adults, connecting older adults with younger patients to share lived experience and guidance.
- Develop midlife transition services to support patients preparing for older age to address age-specific health and wellbeing needs e.g. midlife health MOT
- Include older voices in service design, planning, and advocacy to ensure services reflect the needs of aging patients.
- Promote holistic health, including physical activity, nutrition, mental wellbeing, and social connection.
- Promote financial advice and trusted resources tailored for people with chronic health conditions to reduce anxiety and enable informed decisions in later life.

Appendix

Summary of reflections from the breakout discussions

What life milestone are you most proud of reaching? What or who helped you get there?

Celebrate personal achievement and growth: publishing a book, completing a counselling course, surviving to adulthood, and learning life skills were celebrated as major accomplishments.

Family and legacy: grandchildren, parenthood, and the memory of lost family members and children were powerful motivators.

Community and contribution: working in the community and influencing policy highlighted a commitment to societal impact.

Resilience and daily progress: recognising everyday progress and "little wins" as milestones showed a deep appreciation for ongoing personal development.

Power of faith: faith and connection to a higher power were sources of strength and guidance. Community support, inclusion

How has your relationship with pain changed over time and what have you learned

Pain as a teacher: pain was seen as a signal to rest, reflect, and understand one's limits.

Acceptance and integration: some embraced pain as part of their identity and life journey.

Empathy and support: experiencing pain led to greater awareness of others' suffering and a desire to help.

Coping strategies: techniques like distraction, seeking professional help, and stillness were used to manage pain.

Self-awareness: a shift toward understanding the root causes of pain and responding with care

Lifestyle changes: a shift towards patience and moderation, meditation practices and spiritual or religious grounding

How has caring for someone, or receiving care, changed how you see relationships and strength?

Compassion and consideration: participants expressed a desire to reduce stress for loved ones and encourage rest.

Parenting and adaptation: caring for children, especially those with health conditions, reshaped parenting styles and priorities.

Planning and preparedness: the need for accessible housing and awareness of co-morbidities highlighted the importance of forward-thinking.

Family planning: need for honest prior conversations about genotype implication on partner selection and childbearing, anticipation of children's questions, ethical implications and emotional turmoil

Parental confidence: knowledgeable parents who are emotionally supported raise children are confident in themselves and positive about future

Support networks: recognising the value of strong, reliable support systems in navigating care responsibilities.

How has your view of yourself and your condition changed as you've aged—and what advice would you give the next generation?

Self-awareness and advocacy: gaining insight into one's condition and learning to speak up were key developments.

Knowledge and resources: acknowledgement of increased access to care, support, and information over time.

Resilience and motivation: encouragement to "keep going" and stay connected to personal motivators.

Practical wisdom: advice like dressing appropriately for health conditions reflected lived experience and practical learning.

Financial insight and adaptation: reflections on changing perspectives around life expectancy with age and financial planning for later life, including concerns about having an adequate state pension due to periods of under employment. Importance of paying into work pension schemes.