

## Understanding the Lives of Older People with Vision Impairment

This publication summarises research commissioned by Thomas Pocklington Trust to investigate the needs and aspirations of older people with different eye conditions living in community settings in England. The study reports diverse views from some of the oldest old and those from a variety of cultural backgrounds, showing how everyday lives are personally and socially interdependent. The research was conducted by Sheila Peace, Jeanne Katz, Caroline Holland and Rebecca L Jones from The Open University.

### Summary findings

- Many participants lived with vision impairment (VI) alongside other short and long term health conditions. This required individual assertiveness and practical, social and environmental support.
- Becoming vision impaired in later life entails learning new skills, accepting interdependence and learning to benefit from technology.
- The ability to access appropriate services depends on location and high visibility of both statutory and voluntary organisations.
- Participants emphasised the importance of staying in community-based homes. Spatial orientation is supported through familiarity and control; yet a loved home may not protect against isolation and loneliness.
- The most effective support for people from Black and Asian minority ethnic groups came from their own community VI groups rather than mainstream VI organisations.
- Most participants had incorporated VI as part of their identity and accepted it.
- Most participants maximised their independence through 'responsible risk-taking'.



## Background

Almost two million people living in the UK experience sight loss, particularly as they grow older. Fifty per cent of people aged 90 and over are vision impaired. Women, poorer people, and those from Black and Asian minority ethnic communities (BAME) are more likely to be living with sight loss in later life.

Thomas Pocklington Trust (TPT) commissioned a team from The Open University to consider the needs and aspirations of older people with vision impairment, building on their earlier work involving older people with high support needs. TPT was concerned in particular with housing and 'staying put' in later life.

## Research aims

The study aimed to enable older people with vision impairment living in community environments to express their preferences for where they wished to live and with which types of support. The researchers wanted to understand: choices over lifestyle and living arrangements; how sight loss impacts on a person's identity; and how control and personal autonomy can be maintained or delegated.

## Research methods

This in-depth qualitative study took place in 2015. The researchers worked with an advisory group including people with vision impairment, key stakeholders and TPT staff. The aim was to interview 50 older people, plus some care-givers – family, friends and professionals.

The sample of people with vision impairment included:

- a substantial number aged over 85
- a range of eye conditions
- people from minority ethnic groups

Most participants were reached through national and local voluntary VI organisations across England. Older people not in contact with VI specialist organisations may have different experiences.

50 older people with VI were interviewed and conversations were recorded with participants' informed consent. Photographs were taken where appropriate. The following topics were discussed:

- Visual and general health
- Housing
- Support and interaction
- Living at home



- Activities of daily living
- How to spend the day
- Going out
- Social isolation and loneliness
- Self-worth, pleasure and the meaning of living well

Interviews with paid workers, relatives and volunteers contributed to understanding the context of peoples' lives and the obstacles service providers face.

## Characteristics of participants

Of the 50 older people interviewed, 36 (72%) were female and 14 (28%) male. Just over half were widowed, while 32% were married, the remainder being divorced, separated or single. The majority self-identified as White British, with 18 identifying as Black British, Asian British, Asian, European, Black African or mixed race. Ages ranged from 69 to 99 years, with a mean average of 79 years. On average, BAME participants were younger than the white British participants.

Participants described their sight conditions as follows:

- 17 Age-related macular degeneration (AMD)
- 5 other single conditions including glaucoma
- 12 multiple sight conditions
- 10 sudden loss, trauma or illness-related sight loss

Some were unclear about their diagnoses or reported no definitive diagnosis.

Of those whose sight loss was registered, 17 stated 'blind', 7 'severe', and 7 'partial'. When people had had VI for a long time, re-definitions such as to 'Sight Impairment' (SI) and 'Severe Sight Impairment' (SSI) were confusing.

## Findings

### Living with multiple conditions

Most participants reported additional health conditions: primarily mobility problems (e.g. arthritis), heart or circulatory issues, diabetes or thyroid complaints. While a quarter said mobility issues affected their ability to go outdoors, almost half rated their health as very good. Unsurprisingly, with some exceptions, the oldest participants graded their health as poorer.



## Housing and living arrangements

Most participants lived alone or with their spouse, with very few living with adult children. A majority (68%) were owner-occupiers; 14% social renters; 8% lived in accommodation owned by family members; and just 2% rented privately. Some were uncertain or did not disclose who owned their home. Participants lived in all housing types, from detached to terraced houses to bungalows and one bedroom flats in villages, towns and cities. Almost two-thirds (64%) had lived in their current home for over 20 years.

When describing their housing preferences, participants focused on design, suitability to health needs and financial considerations including downsizing. They prioritised location, safety and quietness, accessibility to transport, local family members (usually daughters) and recognisable communities.

## Adapting housing

Many participants had made adaptations, often in response to physical impairments experienced alongside sight loss. Adaptations included: stair lifts, indoor rails, ramps to front and rear doors, higher WC pans, bath and shower arrangements. Alterations specifically for vision featured wet rooms - especially downstairs - and indoor and outdoor guide rails. Kitchen improvements included better lighting, colour contrasts and window blinds installed to reduce dazzle.

Many participants had difficulty finding the appropriate statutory organisation to assess their homes for adaptations and consequently paid for these themselves, or did without.

## Assistive technology

Irrespective of educational level or degree of sight loss, participants were extremely knowledgeable about the cost, availability, sophistication and complexity of the latest models of vision aids and assistive technology. They obtained information from relatives, friends, local or national agencies. Devices were sourced by participants or relatives, or provided by local vision organisations. However, the most sophisticated devices were often too expensive to acquire or update.

Many participants used magnifiers (often several, in different rooms) and reading devices including Optelec, for image enhancement. Liquid level indicators were familiar to most, as were labellers (Penfriend) and markers on domestic equipment. Some had specialised lighting, talking clocks and scales and adapted computers. Bus hailers were used by some participants.



## Coping at home

Participants spent much of their day at home. Most felt safe in their own environment although they worried about falling or tripping. Levels of daily activity related to their mobility, vision, feelings of well-being and support. There was considerable variation between participants who could self-care (cook, wash and dress themselves, clean their homes) and those who struggled with these tasks. Many relied on radio, TV and talking books for company; yet many reported feeling lonely.

## Getting out and about

Most participants equated losing their sight with losing their independence. Going outside was challenging. Some only went out accompanied; others often required a stick both for support and to identify some vulnerability. Nine used ordinary walking sticks while eighteen used white sticks. Venturing alone on treacherous pavements meant taking calculated risks. Nevertheless many participants persevered in navigating their local areas - indicating their determination for independence. They memorised specific routes, navigable pedestrian crossings and bus stops; changes in pavement design and removal of designated crossings posed severe challenges. Guide dogs enabled three participants to feel secure and confident outdoors.

Participants particularly valued going out on excursions and to socialise. However these trips mostly relied on lifts from friends or partners rather than public transport. Former drivers missed the pleasure, independence and freedom of driving themselves.

## Living interdependently

Most participants maintained active roles in their families and communities, often with the support of others.

### (a) Support from family, friends and neighbours

A third were living with their partner, giving each other considerable daily support - but some worried about future life alone. Yet many already living alone described receiving help from local family members as well as friends and neighbours. Without such assistance, managing daily tasks was difficult; those anticipating deterioration were considering alternative housing.

### (b) Support from organisations

Local groups supporting people with VI provided much advice, friendship and practical help, including transport to appointments, regular local meetings, talks from various



speakers and holiday breaks. Practical or cost reasons prevented some from participating, but for most this was their social lifeline.

People from minority ethnic groups primarily joined organisations serving their own communities; their organisers liaised regularly with local and national VI providers.

Participants had difficulty recalling what services they received from statutory agencies other than ophthalmic hospital/community teams. A few had home carers helping them with personal care. Many paid for cleaning services and/or help in the garden, according to their needs and finances.

## Quality of life

Participants varied when rating their quality of life (QoL). Those describing a better quality of life also rated their health as good or very good. The very few who described their QoL as low were either in very poor general health, or were struggling financially and living alone: they expressed feelings of loneliness, 'uselessness', and wanting more support. These participants gave very negative accounts of their lives, emphasising their loss of control and independence.

Many participants reported feeling down occasionally, missing former pastimes, but most focused on minimising their difficulties. For example, one person said, "From time to time I get very depressed and have a little weep. And then I pick myself up."

When asked what would make their lives easier, many spontaneously replied that it was regaining their vision, or a greater degree of it. Other more 'realistic' ambitions included specific aids and adaptations, such as downstairs toilets or more frequent opportunities to get out.

## Conclusions and recommendations

- Older people with VI maintain a positive attitude and live good lives when supported by family, friends, local and national organisations.
- To maintain independence and enable people with VI to remain in their choice of home and community, access to different forms of support is essential.
- Knowing who to contact for reliable and accessible information, advice on housing adaptations, social support or useful devices, is critical.



- Engaging with organisations is a vital lifeline for vision impaired people. All organisations need to be pro-active in building partnerships and reaching out to users.
- Liaison between ophthalmic and statutory services with voluntary VI organisations is crucial because people with VI have a range of sight impairments, diverse life experiences, contacts and resources.

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The study reported here is independent research commissioned by Thomas Pocklington Trust. The views expressed are those of the authors and not necessarily those of Thomas Pocklington Trust.

## How to obtain further information

This paper is a summary of the full report entitled 'The Needs and Aspirations of Vision-Impaired Older People' which is downloadable from [www.pocklington-trust.org.uk](http://www.pocklington-trust.org.uk) or on request from:

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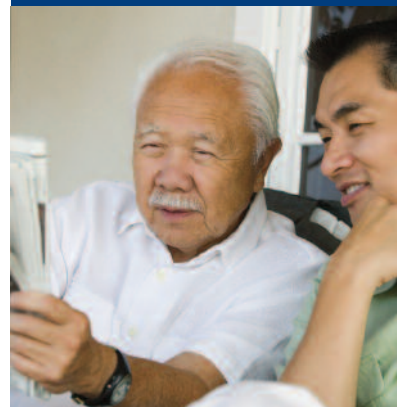
In this publication, the terms 'vision impairment' and 'sight loss' are used interchangeably.

## About Thomas Pocklington Trust

Thomas Pocklington Trust is a national charity dedicated to delivering positive change for people with sight loss.

Research is central to Pocklington's work. The research we fund supports independent living and identifies barriers and opportunities in areas such as employment, housing and technology.

We work in partnership and share our knowledge widely to enable change. We provide evidence, key information and guidance for policymakers, service planners, professionals and people with sight loss.





for people with sight loss

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