

## **Travelling well with dementia**

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### **1 Introduction**

Keeping active and remaining connected with our community is good for our physical and mental health. For most of us this is likely to include using some form of transport. A reduced ability to travel, for whatever reason, can therefore discourage people from going about their day-to-day activities such as working, shopping or visiting friends and family.

This is particularly true for people affected by dementia for whom remaining active and socially connected is a key part of living well. Dementia can affect much more than memory; it can make it hard to think clearly and can affect balance, coordination, spatial perception, the ability to plan and follow processes and communication. It may even affect feelings and mood. Every person living with dementia will be affected in different ways. Given that travel can be noisy, busy and disorienting, the challenges that can accompany dementia are likely to mean that travel can become increasingly daunting as the condition progresses.

Alzheimer Scotland reports that an estimated 93,000 people have dementia in Scotland today<sup>1</sup>. According to The Scottish Government, there were an estimated 16,712 people newly diagnosed with dementia in Scotland in 2014. This number is estimated to increase by 17% to over 19,000 in 2020<sup>2</sup>. Although dementia is associated with older age Alzheimer Scotland estimate that around 3,200 of people living with dementia in Scotland today are under the age of 65.

If this growing number of people living with dementia are to continue to travel and maintain their independence then transport and related services need to understand the experience of travelling with dementia and respond by developing services that are informed by real-life experience. Upstream is a project aiming to help transport service providers to achieve this by working with people living with dementia across Scotland, to discover and share their travel experiences and develop training and processes for transport service providers that turn these insights into positive action for change.

Upstream ([www.upstream.scot](http://www.upstream.scot)) is funded by the Life Changes Trust<sup>3</sup> and supported by the ESP Group<sup>4</sup>. The Upstream team began the project in March 2016.

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## **2 Methodologies**

### **2.1 Working across Scotland**

We want to explore the differences and similarities of travelling with dementia, around the various and different geographical regions of Scotland and have been working in the Western Isles, Aberdeen and East Lothian. Close collaboration with the Life Changes Trust means that we have been able to link with existing Dementia Friendly Communities projects in Aberdeen, East Lothian and the Western Isles, providing connections with groups of people who are already getting together to support each other. This is important as we can meet with people affected by dementia in safe, familiar surroundings and contexts, complementing and hopefully enhancing local support activities.

The Western Isles are a perfect area for Upstream to learn, with a combination of public transport links (minus the trains) and the added reliance on air and sea links with the mainland. We are working closely with the Dementia Friendly Community project at An Lanntair along with Alzheimer Scotland, visiting various groups in Stornoway and more remote locations to meet with people with dementia and learn about their specific challenges. The local use of gaelic and the remote nature of many communities can bring different dimensions to conversations about getting around, compared to those on the mainland. Of particular interest is the regular use of air and sea to enable people to attend medical appointments, usually in Inverness but also further afield.

In East Lothian Upstream is working closely with Dementia Friendly East Lothian. In addition to collecting insights and ideas Upstream workshop methods have been used by the North Berwick Coastal Area Partnership as a way to explore local transport priorities, with the aim that voices of people with dementia will be heard during local planning discussions.

Working closely with the dementia-friendly communities project hosted by Aberdeen Council of Voluntary Organisations (ACVO) and Alzheimer Scotland we are working with people living with dementia in Aberdeen City and exploring links with local transport operators and planners. Upstream has held workshops at the Alzheimer Scotland resource centre and learned about the challenges of getting about the city as well as the rural surroundings of Aberdeenshire.

### **2.2 Working with people affected by dementia**

Working with people with dementia lies at the heart of the Upstream approach. We use creative methods to encourage and enable conversations about mobility. Everybody has a contribution to make - whether it is a present day experience or a memory of past travels. By creating the right context and framework for conversation we can hear about the whole experience of getting out and about, from planning the journey to buying tickets, from finding a parking space to waiting at the bus stop. By talking about mobility

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rather than transport - generally getting out and about - we explore the crucial stages before and after, as well as during, a journey.

Upstream's approach provides a range of ways in which people can participate, offer their ideas and share their experiences. Instead of a formal interview process, we utilise creative participatory methods such as asking people to sketch their favourite ways to travel and invite them to draw a picture or map to describe their journeys. We also ask what's good, what could be better and then encourage groups to ask questions.... I wonder why? or Imagine if...? Transport can be complex and a little explanation can go a long way to enabling people to understand why things work, or happen, in a certain way. All kinds of ideas and discussion points come from these activities. Why are pedestrian crossings an inconsistent design? Why is the information on a bus stop so high up? Why does the blue disabled badge still have a picture of a wheelchair on it? Imagine if tickets were colour coded or if we had more time to understand questions or deal with money.

While these methods have been designed to ensure that the voices of people living with dementia are heard and that everyone can contribute, they appear to work well with any group. We would encourage anyone who wishes to facilitate conversations about mobility to try them.

We sometimes ask people to 'send a message' to transport operators. We have had a variety of responses including:

*'Is it better to use National Concessionary Card or Senior Railcard? Make it Simple!'*

*'Consistency is very important'*

*'Thank you for being helpful most of the time with my Father-in-Law who has Alzheimer's ... but could you look at changing the bus time table to make it more easy reading?'*

*'...please help if you see someone struggling. Always smile. Thank you for your service'*

These few messages reflect themes in the stories that we hear – that people affected by dementia can find travel experiences difficult, they might lose their confidence or experience increased anxiety. The importance of consistency and familiarity is often discussed and, above all, the need for increased awareness about dementia. Good staff attitude and customer-focussed service is important, even if processes and infrastructure does not yet meet particular needs.

We also hear many stories about the difficult transition of giving up driving after a diagnosis of dementia. Relying on public transport is a new experience to many and can be a daunting experience for those who have not done so for a long time.

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## 2.3 Analysing stories and insights

The written and verbal feedback and conversation points during our workshops provide insights, as do blog posts, newspaper articles, radio interviews or chance encounters – all can reveal useful information about travel challenges or the ways in which people overcome them.

We have listened to stories, analysed and grouped insights into broader descriptions of challenges that people affected by dementia can face and described this as the Upstream Lens. Rather than simply providing mobility service providers with individual examples of things that could be ‘fixed’ we also want to provide a more comprehensive ‘Lens’ through which they can view and assess their processes, procedures and services. Not only does the Lens show the key areas of concern for people affected by dementia along with specific examples, it can also show a growing collection of solutions and opportunities - examples of where people are already working towards, prototyping or implementing solutions

## 2.4 Working with Transport Service Providers

The Upstream team has used these insights and stories to inform, design and trial different training formats that allow operators to appreciate the challenges of travelling with dementia. Importantly we are creating opportunities for people affected by dementia to work directly with transport operator staff.

### 2.4.1 Conversations with people affected by dementia

To date Upstream has arranged for a service provider to join us in two of our group conversations with people affected by dementia. In both cases the staff commented on the value of being part of the discussion. This is described in a blog post<sup>5</sup> after a representative from First Aberdeen had joined us for a workshop.

*‘He reflected afterwards that sometimes the small things can make the biggest difference. He also wondered about who he could bring back with him next time - it’s important for other colleagues to be part of the conversation. Of course, he could take the notes and questions back with him, but to really get a sense of what’s important, you had to be there’*

An important lesson from these interactions was that this is a two-way conversation. Whilst Mobility Service Providers have much to learn about the challenges of travelling with dementia, we all have much to learn about the complexities of providing mobility services if we are work together to build more enabling transport.

### 2.4.2 Training workshops

Upstream delivers introductory and more focussed training sessions for service providers that introduce staff to dementia and the importance of continuing to be independent and travel well with a diagnosis, sharing the learning from our work. We take staff through activities that help them to consider their service, using participants’ new knowledge of the challenges that dementia can bring. Importantly, we

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invite staff to consider how enabling their own service might be before someone travelling with dementia. This often prompts new ideas about how services might be improved.

These training sessions have been used as preparatory work for shared experiences described below.

### **2.4.3 Shared Experiences**

While working with people affected by dementia and service providers separately can reveal useful insights and provide opportunities for people to contribute, we believe that the most powerful learning experience is to bring people affected by dementia together with those providing services to experience each other's challenges and develop a shared understanding of potential solutions. Ideally, this means experiencing a service together.

During the early stages of the project we learned about the work of the British Transport Police in North East England who were developing 'supported journeys', accompanying people affected by dementia on short rail journeys to improve their confidence to travel again<sup>6</sup>. We have extended this model by organising a journey for staff and people affected by dementia to take together - a shared journey - taking the opportunity to not only improve passenger confidence but also for staff to learn about travelling with dementia at first hand.

We have trialled this approach in two locations to date.

In September 2016 we delivered a series of workshops on travelling well with dementia to ca 45 mobility staff at Waverley Station. Working in parallel with a carers group, we designed an experience with staff that would allow people affected by dementia to learn about assistance available to them while staff would have a chance to travel or meet and learn from people affected by dementia. We planned a journey that would incorporate the workshops as a preparatory phase and a dementia-friendly theatre performance as the journey destination. Through our connection with Dementia Friendly East Lothian we invited members of Dementia Friendly Dunbar to trial this approach with us.

Upstream coordinated a day that enabled members of the carers group to travel with a Virgin Trains East Coast (VTEC) Manager to Waverley station, tour and explore the facilities, discuss ticketing, concessions, signage and more. The group then travelled onto the theatre by taxi for a dementia-friendly performance.

We have taken a similar approach at Aberdeen Airport, using introductory workshops and Dementia Friends sessions delivered by local Alzheimer Scotland staff to prepare staff for a shared experience. We returned with the local Positive Dementia Group, where we worked with staff, walking through check-in procedures and the security process. Staff discussed and demonstrated assistance that is available and members of the Positive Dementia Group shared experiences and opinions. It was a valuable experience for everyone concerned and several members of the group reported feeling more confident about considering air travel again<sup>7</sup>.

### **3 The Upstream model for service improvement through training**

Upstream aims to support service providers through a training process that builds on dementia awareness, develops a deeper understanding of the challenges of travelling with dementia and ultimately leads to service improvement. Our process is designed to provide opportunities for participation and enable people affected by dementia to be active partners, contributing their insights, experiences and stories to create training experiences that make a lasting impact.

### **4 Conclusions**

The Upstream project has uncovered significant insights from people affected by dementia suggesting that people lose their confidence to travel and are anxious about the experience. A key conclusion of the work to date is that, often the issues are related to stigma and a lack of awareness about dementia. This places a great importance on addressing staff attitude and understanding, if we are to design transport that works for everyone. The Upstream project has found that providing experiences, such as the 'Shared Journey' method, that allow operator staff to understand what it is like to travel with dementia and to appreciate the value of making services more enabling, will begin to build services that respond to the needs of all passengers. Upstream plans to develop its education and training further, providing new experiences for mobility service providers and people affected by dementia, bringing them together and providing a framework for inclusive service design. The Upstream project, however, has also highlighted the importance that training can turn awareness into action. By developing knowledge about dementia and helping staff to explore the challenges it can bring in a specific service setting, we aim to foster service design and delivery that responds to the needs of travellers affected by dementia. By involving people affected by dementia as active partners in this process, we want to make this service design as inclusive as possible.

The Upstream project has identified some key transport experiences, where more research is required to understand how improvements can be made for people affected by dementia. At the forefront is the area of driving and the process of giving up driving after a dementia diagnosis. These are issues that are often discussed by people affected by dementia. People with a diagnosis can, in many cases, continue to drive. However, when the time comes to stop, the transition to public transport can be a challenge, particularly for those who have not used it for some time. In addition to this, the Driving Assessment process can be a difficult experience as can conversations with family and carers about stopping driving.

It is clear that changes can be made to the transport network and to individual transport service to better support the growing number of people affected by dementia by allowing them to continue to travel. Upstream has begun to highlight some first areas of improvement. Upstream, however, has also shed light on the importance of 1) developing inclusive processes for designing service improvements and 2)

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staff training. Services that are truly responsive to the challenges of travelling with dementia can only be developed if people living with the condition play a central role, providing insights and experience and advice. The next phases of the Upstream project intend to facilitate this by creating spaces for new conversations and processes for turning insights into positive action for change.

## 5 References

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## 6 Authors

Andy Hyde is an experienced independent practitioner who has many years of experience working with people to develop and influence local services that can improve their health and wellbeing. He has developed and implemented inclusive processes that ensure voices are heard, valued and included in service design and community planning. He has a particular interest in people-powered innovation.

Beth Garner is a Future Mobility Design Consultant at Viaqqio, part of the ESP Group. ESP Group makes transport work for millions of travellers every day through integrated customer support services and technology. Beth has led collaborative mobility projects in UK and North America and has a specific expertise in user-centred research and business models linked to emerging mobility services. She is currently leading activities to co-design and develop a series of innovative mobility services tailored to specific user lifestyle needs.

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