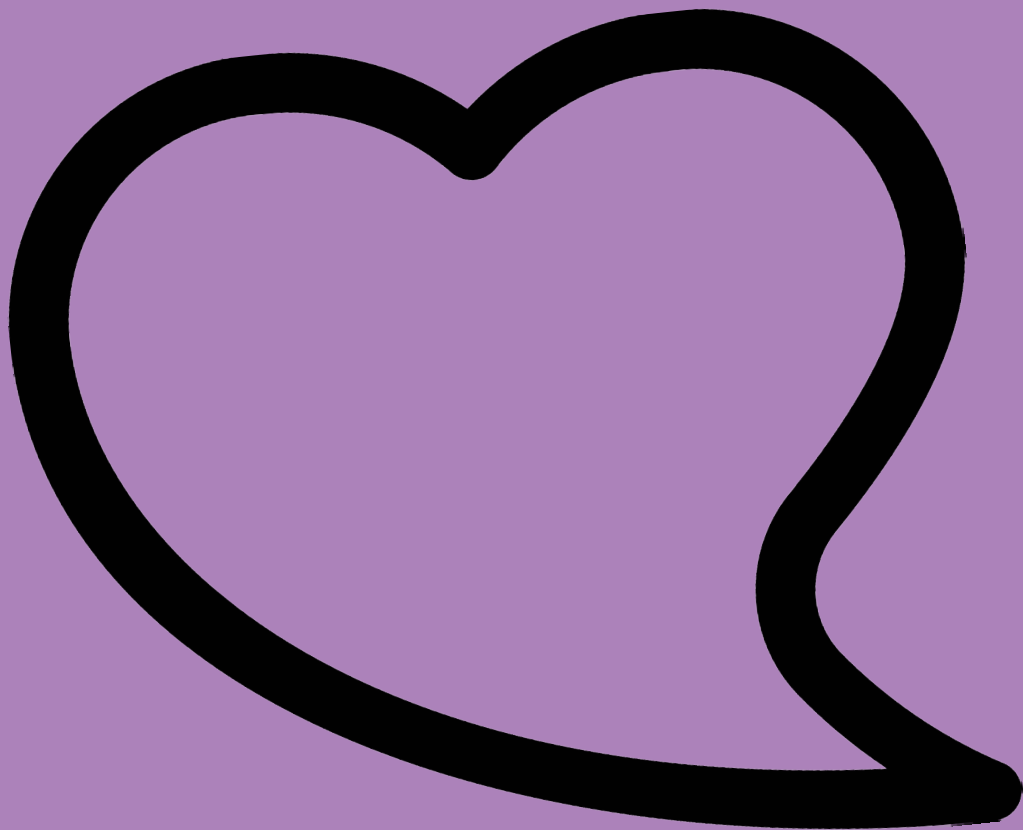




The *Care Cameos* series is designed to present short but challenging sketches of various issues and to provide a forum to encourage and foster debate on a whole range of issues important for the delivering of care and support for older individuals across Scotland.

Scottish Care

25 Barns Street
Ayr, KA7 1XB
Co. SC243076



**LET'S TALK ABOUT
SEX...UALITY**

A CARE CAMEO



Preface

I am delighted to introduce this *Care Cameo* to you.

Last year I spoke at a conference on the subject '*Intimate relationships in care: the right to be fully me.*' At the end of my talk I shared an instance of how I had been involved with care staff in a London hospice to support a woman dying with dementia to spend her last few hours together with her life-long lover and partner. The staff recognised that that was what she had wanted and would have done had she been in her own home; they had insight to know that for these two individuals that simple act was not just about dying well but living and loving to the very end. It was about touch, sensuousness, physicality and memory.

The reaction then to my talk and to a subsequent blog post highlighted for me just how little work, with some notable exceptions, had been undertaken in Scotland on the issue of sexuality, social care and dementia. Indeed, what work there had been had largely been from an academic perspective. Yet, as we all know, the lives of people with dementia are significantly influenced and affected by those who care for and work with them, those who live alongside and who are their friends and family.

But all too often the discussions on sexuality and dementia focus on the need to manage behaviour, issues of risk, capacity and consent. The essence of relationship, of intimacy and physicality are marginalised or ignored. Yet for me, sexuality and sexual expression is profoundly a human rights issue. It is this whole gamut of what it means to be sexual and to live a life with dementia which respects individuality and human rights that this *Care Cameo* seeks to explore.

The *Care Cameo* contains a number of narratives and interviews. It starts by telling the story of a roundtable process held in 2017 on the themes of sexuality and dementia and what their main insights have been; it then describes the deeply personal story of the designer John Ross from his jet-set lifestyle to living and dying well with Parkinson's and Lewy Body, offering

insights and perspectives which are both challenging and illuminating. The *Cameo* goes on to explore some of the challenges LGBT people in Scotland experience when faced with a diagnosis of dementia and explains what can be done to address these before considering the experience of older people in Scotland in relation to sexual health. The last set of insights come from the work of the Terrence Higgins Trust and from the results of their recent research into the experiences of older people living with HIV in the UK.

Collectively these stories and contributions offer challenge and promise. They may at times make for an uncomfortable or hard read, but I hope you will read the whole *Cameo* so that you can get a real sense of the issues facing the hundreds of people in Scotland who are living with dementia but also experiencing discrimination and rejection, and the thousands of older Scots who continue to be sexual.

I am very grateful to all our contributors for sharing their conversations and stories, for giving their time and dedicating their skill to writing this *Cameo*. I hope you will be challenged and convinced, encouraged and inspired by the stories they share and the words they offer.

Dr Donald Macaskill
CEO, Scottish Care
@DrDMacaskill



About the Authors

Jenny Dalrymple

Jenny Dalrymple registered as a nurse in London in the 1980s and has spent most of her working life based in NHS sexual health services. She recently completed a PhD exploring late middle-aged adults' risk-taking for sexually transmitted infections and is currently on a clinical academic research fellowship, working in both Glasgow Caledonian University and Sandyford sexual health service in NHS Greater Glasgow and Clyde.

Jennifer Hall

Jennifer Hall is a core member of the Quality & Workforce Development team at Alzheimer Scotland. With over 15 years' experience of working in social care, Jenn now plays a fundamental part in the design & delivery of Alzheimer Scotland's learning and development programmes. Jenn is committed to promoting the human rights of people living with dementia and their carer's and has a particular interest in equality and dementia. Jenn is currently working towards an MSc in Citizenship, Civil Society and Human Rights at Glasgow Caledonian University.

Clive King

Clive King is the acting Training Manager at Terrence Higgins Trust Learning Centre. Clive has been involved with THT Scotland for over a decade, launching and managing health promotion projects, designing and facilitating training, undertaking research and overseeing community outreach initiatives. Clive is also a playwright and lyricist, whose recent works include *Wee Free! The Musical* and *The Real Mrs Sinatra* at Oran Mor in Glasgow.



Introduction

"...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors."

WHO - 2006

Sexuality, as defined by the World Health Organisation, should be afforded to all adults; therefore, people should not be discriminated against because of a dementia diagnosis. The taboo of sexuality and ageing is challenging enough without considering what this may come to mean for someone living with dementia, their sexuality and their intimate relationships.

This Care Cameo will illustrate some of the key issues the authors have encountered in relation to sexuality and dementia, to give us food for thought and to ensure that a holistic, human rights approach fully encompasses a person's sexuality as an integral part of self.

Bringing People Together

In May 2017, Scottish Care, Alzheimer Scotland and Terrence Higgins Trust brought together a wide range of practitioners and individuals with lived experience around the table to expose and explore the issues people were experiencing in relation to their sexuality and living with dementia. We wanted to constructively identify barriers and opportunities to protect and realise the sexual rights of people with dementia, supporting the goal of an enjoyable, safe and healthy sex life for all.

We facilitated 2 meetings which focussed on the following key areas:

- Ensuring people with dementia are free to express their sexuality
- Protecting the sexual rights of people with dementia
- Opportunities for new partnerships or developments that can support people with dementia in sexual expression and to maintain a healthy sex life after diagnosis
- Workforce Development: Supporting care staff to enable individuals with dementia to live their lives to the fullest sexual expression

When we asked participants WHY this issue is important, they told us:

“Sexuality is not just a Scottish phenomenon - it’s a global issue and we need to get better at discussing it.”

“When it comes to sexuality, particularly sexual expression, we enter the territory of a person’s right to autonomy, choice, control, dignity and respect – all of which can be called into question when a person has dementia.”

“We are all sensual beings to our last breath.”

“When a person develops dementia parts of their identity are stripped away; their sexuality is not acknowledged or important.”

“People’s relationships become secondary, my identity as their partner is seen as ‘main carer’, it devalues our love and who we are in relation to each other.”

“In my 20 years experience of working in residential care couples are still being split up in care homes and the idea of a person wanting to have a double bed is an alien concept.”

“The impact of touch is huge in the final stages of dementia, even hand holding can be taboo.”

“Discussions centred around sexuality and dementia are often met with resistance. This is often because of attitudes towards older people being seen as asexual or sexuality not been seen as anyone else’s business but the person’s. We need to challenge these attitudes and perceptions.”

“Sexuality and dementia poses complex issues around capacity and consent. How do we get this right for everyone?”

“Conversations of sexuality in care settings are almost always negative and only ever become visible when there is a concern about safety. What about positive interpretations of sexual expression?”

“When I got my diagnosis of dementia nobody ever asked me about my sexuality and if this was important to me. I felt silenced and worried about when the right time to tell people involved in my care about my sexual orientation would crop up.”

The space created at the round table discussions gave us the opportunity to deepen our understanding of the issues that arise in practice. The topic of Sexuality and Dementia has multiple layers of stigma that can be a barrier to people living well. To change this, it will not only require awareness raising through conversations but also through skills practice, workforce training and development and clear messages in our current legislation and care frameworks; it will require clear leadership from Scottish Government and regulatory bodies that relationships and sexuality

matter.

Our second meeting took place in July 2017. The discussions at this meeting allowed us to explore in detail the issues arising within the workforce and what we can do to address these:

Sexuality in [dementia] care settings is still taboo – Conversations don't appear to have moved on far in the last 30 years...

- Participants reported a lack of sexuality training and/or awareness, particularly at induction level
- Sexuality training is rarely mandatory – All staff need to be aware
- Staff lack opportunities to upskill and build confidence in having conversations with people they support
- LGBT Identities are underrepresented in care and lack visibility
- Sexuality has no or limited place in assessments and support planning. Individuals often want to discuss/explore this but are not given an opportunity
- There is a lot of knowledge and skills within our workforce but how does this apply in practice?

Frontline workers explicitly reported a lack of confidence in:

- LGBT identities and dementia
- The need and value of talking about sexuality as a human right
- Generation gaps; recognising that older people have sex and may want to express their sexuality
- Defining and understanding (in the context of dementia):
 - Sex
 - Sexuality
 - Sexual health
 - Relationships
 - Touch, intimacy, affection
 - Need for human contact

Risk Adversity

- There is a very strong focus on legal capacity and consent
- Understanding and managing real and perceived risk and historical

issues

- Fears around scrutiny from regulatory bodies – understanding and balance
- HIV Stigma – exaggerated fear of transmission, disclosure and confidentiality.

Having had the opportunity to highlight the pertinent issues raised around sexuality and dementia, participants were encouraged to act on what they could reasonably take forward in their practice settings to influence positive change.

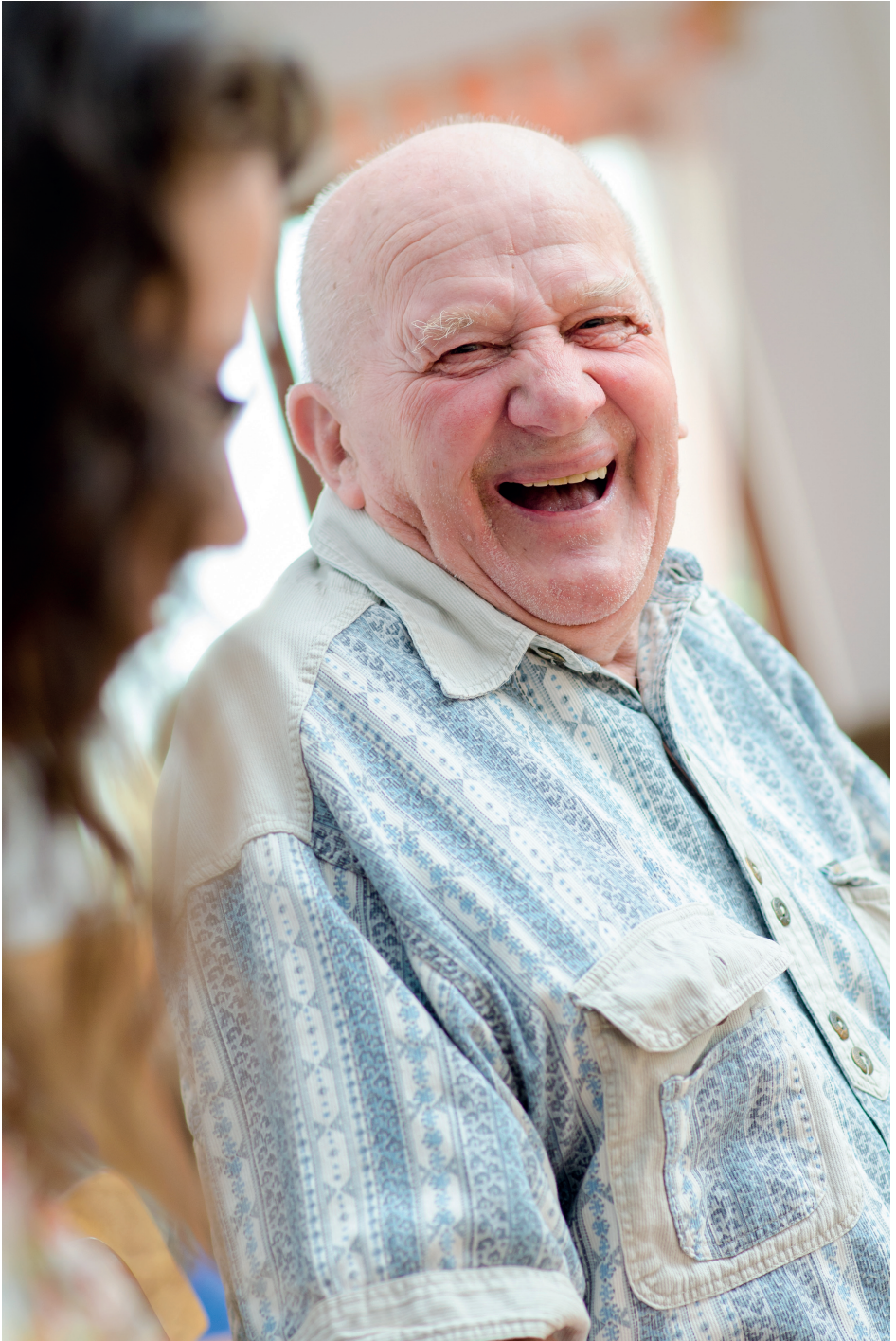
Sexuality and Dementia Training Programme

One of the developments that has happened since the sessions in 2017 is a collaboration between Three Sisters Consultancy and Alzheimer Scotland to design a bespoke training programme that addresses the areas highlighted over the course of the round table discussions.

On completion of this programme participants will be able to:

- Examine the importance of sexuality in dementia care
- Illustrate awareness and understanding of the diverse nature of sexuality
- Demonstrate confidence and skill when supporting people with dementia to express their sexuality
- Feel empowered to balance individual rights to sexuality with staff member's right to a safe working environment
- Navigate the complexity of consent, and feel confident continuing to do so in their role
- Understand the importance of including sexuality in care planning processes
- Feel enabled to understand individual sexual needs and how these may be expressed in behaviour and support people to manage these needs appropriately.

For more information or to attend this training please contact:
dementiatraining@alzscot.org



John Ross: A Design for Living

Designer, Stylist, Art Director and Author John Ross tells his life story to Clive King, Training Manager at Terrence Higgins Trust Scotland.

I was born in Glasgow in the fifties. None of the rest of my family were creative but I could draw before I could talk and I was fascinated by design from a very young age. Although my first love was always fashion, at 15 I won a design competition run by the famous carpet company Templetons. Even though I was up against professionals, I landed first place. This was in the same month that I won a nationwide television talent contest for young people called Anything You Can Do. And at that point it really did feel like I could do anything!

Off the back of the competitions, I designed my first fashion collection and found myself all over the press as the “next big thing”. As a result, at 16, I was offered a job designing clothes for a new chain of Scottish stores called Virgo. They were pioneers of fast fashion on the high street and I designed their store interiors as well as clothes. My life changed overnight. Suddenly this teenage boy from Rutherglen was travelling and working in London, Paris, Milan, Florence, Hong Kong, Taiwan, Korea, Athens, Frankfurt, Zurich, Tel Aviv, Bombay and Copenhagen. Staying in first class hotels, and meeting all kinds of colourful and interesting characters, I felt like I had been propelled into the jet set!

At 18 I was head designer for a group of 110 stores. That was also the age I got married and, a year later, I became a father. The day my daughter was born was the happiest day of my life. But the work was high pressure and it got to the point where I would wake up not knowing what country I was in. This was in the days before mobile phones and email so I was dashing all over the globe delivering my designs, collecting samples, visiting factories, usually working from seven in the morning until midnight. Being away from home eight months a year took its toll on my relationship with my wife and the marriage ended in a bitter divorce. I loved my daughter and found myself locked in a brutal custody battle that threatened to emotionally destroy me.

Not long after separating from my wife I met and fell in love with a beautiful, vibrant, eccentric, vivacious, married dancer. She was Scottish but lived in

Amsterdam. We had a ball clubbing and partying, living like there was no tomorrow. I had been in both a car crash in Scotland and a plane crash in India by this time and felt like I deserved some love and laughter in my life.

Despite the overwork and exhaustion, life was great. My career was going well, I had a nice car, a lovely house and a sensational girlfriend. Then one night in a private club in London my life took another unexpected and dramatic turn: I fell head over heels in love with a half Lebanese half South American boy.

Sexuality was no big issue in my world. Love was what mattered and I have always believed that the soul has no gender. And this was the early eighties, when it seemed like just about everybody in the world was bisexual! When my boyfriend's powerful family found out about our relationship he was sent to Zurich for an arranged marriage.

Disenchanted and disillusioned, I sold my flat, sold my car, got rid of everything and moved to America. After a period in Los Angeles, I upped sticks to San Francisco and worked for an exclusive boutique making clothes for pop stars and celebrities. Every night was party night in 'Frisco and it didn't take me long to climb aboard the roller coaster of film premieres, crazy house parties, extravagant night clubs and the wonderful quirky nightlife of the Castro. But even then the dark cloud of AIDS had started to loom over the city, as one young man after another succumbed to the terrifying new condition they were calling The Gay Plague.

I stayed there for two years and was deported because my work visa didn't come through in time to avoid President Reagan's cull of foreign nationals. So then I went back to Europe where I landed a job as head designer for an international fashion house in Netherland.

The whirlwind started up again as I designed for various collections and found myself featured on the hit BBC programme The Clothes Show. Around that time, I started to art direct the photo shoots for my clothes and those of other designers. I discovered I had a flair for coming up with the visual concept, choosing the models, the locations and working with photographers. It opened up another avenue for my creativity.

I launched my own collection and when a film star saw my work, she wanted my clothes for a shoot and suddenly I was catapulted into the world of movies, pop music and fashion editorials. One day I was working on

a magazine shoot when my phone rang. It was the lead vocalist from 2 Unlimited. They were doing a big show for the Sultan of Brunei and they asked me to design all the clothes for it. This was the beginning of a close relationship. I made lot of clothes for them together with Dutch designer Desiree Webers and styled for their concerts, videos, photo shoots and award shows. 2 Unlimited had sold 30 million albums worldwide. They travelled all over the globe with their entourage. They had won multiple awards year after year as best dance act at the Music Awards in Monte Carlo and had also picked up many MTV awards. Working with them was like being propelled into a tornado.

I met lots of stars, which was very inspiring. I had worked with beautiful models before and it was nice to see my designs on supermodels but even more amazing to see my creations come to life on megastars. Anita, the singer, was a pleasure to work with and she remains a true friend to this day. When 2 Unlimited disbanded to pursue solo careers I continued to work with them individually.

I also had dozens of other clients like boy band Caught in the Act, Victoria Wilson, James of the Shamen, Ruth Jacot, 2 Brothers on the Fourth Floor, Tatiana Simic and lots of new artists. I was also designing and working on advertising campaigns and fashion magazines' editorials with top international models.

When you're a key part of a pop star's entourage, you work while they sleep. Then night comes and you get caught up with all the parties and socialising. It sounds glamorous but it's an exhausting lifestyle. So I moved again, this time to Thailand, and really didn't do a lot of work for a while. There I immersed myself in the buzzing metropolis of Bangkok, a true melting pot of cultures and traditions, as well as the lush tropical island of Phuket and the captivating unspoiled Phi Phi islands. I still freelanced a bit, flying off to wherever to do a video or a photo shoot, but otherwise I felt I deserved a rest. Everyone thought I was mad, passing up lots of opportunities. Given what happened subsequently, I'm very glad I took that "me time".

After a number of years living in a palatial beachside apartment with breathtaking views, I decided it was time to come home to Scotland. After years of separation, I reunited with my daughter and we got on famously, making up for lost time. I was delighted when she had a child. Unfortunately, he was born with a cleft lip and pallet which meant he

needed multiple surgeries. I was heartbroken, as I loved my grandson.

All my life, I'd nursed a desire to write and started to realise that ambition. I've written seven books, two of which have been published. One is a children's fantasy called *The Golden Boy in Atlantis*; the other is a scandalous romp through the worlds of fashion, film and pop music; I used the pseudonym Thyssen Carlisle for *Lust is a Four Letter Word*.

In tandem with the writing, I took another design job with a Glasgow based fashion company but they had a change of direction and I was made redundant at the end of 2014. Two weeks later my hands started to shake and my legs started to drag. At first I thought it was just stress, due to the unexpected loss of my day job, and the initial diagnosis was vertigo coupled with anxiety and depression. But the symptoms got worse and eventually I was referred to a specialist who broke the news that I had Parkinson's Disease.

They gave me massive doses of Sinemet, a drug that was supposed to help but made matters worse. Much worse. I started to have horrific hallucinations, sometimes for up to sixteen hours a day. The hallucinations were visual, tactile and always sinister. The first time it happened I was staying in a flat with scaffolding going around the whole building to facilitate roof repairs. I woke up one night and there was a man standing at the end of the bed with piercing blue eyes slinging an enormous meat cleaver at me. So I ran into the hallway, and there were two more men with machetes waiting for me. I thought these people had got in through the scaffolding and were going to kill me so I phoned 999 and they sent an ambulance.

They took me into hospital to monitor me but the hallucinations continued... strange children in Victorian dress, wild animals, all sorts of things. One night I woke up to find my bed filled with tarantula spiders and I could feel them as they crawled across my skin. Another night my bed was piled high with dead bodies – a corpse handed me a dead baby; it was so cold I dropped it, but its shoe stuck to my hand. I thought I was going mad. At first the doctors were baffled. People with Parkinson's do sometimes experience hallucinations, but they can be nice things such as a sunny day on the beach or a visit from Princess Diana or Angelina Jolie. But the visions I was having were always very frightening and very unwelcome.

Finally, after a battery of tests and scans, I was diagnosed with Lewy Body

Dementia. A doctor I hadn't seen before sat me down and said "Mr Ross, you have Lewy Body as well as Parkinson's. I suggest you make a will, contact your family and give them power of attorney". At 61, I found myself facing the triple whammy of Parkinson's, Lewy Body and, just for good measure, arthritis. Worst of all, it was eventually explained to me that the drugs that could alleviate my Parkinson's would exacerbate the Lewy Body. I felt trapped between a rock and a hard place.

I could no longer manage the stairs to my flat, or venture out alone in case I hallucinated in the shops or at the bank, so I had to seek help to find sheltered housing. My flat is cosy and comfortable but most of the other occupants are in their eighties, or older, and I feel out of step with them. I was always used to being around young people. And, as a bisexual man, I don't feel I can be open about my sexuality or my life.

I have seen an army of doctors and specialists and have been horrified how little some of them knew about my illness. That's why I decided to educate myself about my condition. My mental health doctor and nurse at the Glenkirk Centre have been amazing. The staff at the Riverside Mental Health Resource Centre were extremely helpful, putting me in touch with Welfare Rights Officers to sort out my benefits and Support Workers to help me understand my illnesses and navigate everyday life. They also directed me to Alzheimer Scotland, where a wonderful woman called Susan Rendall took the time to help me understand my conditions and start to make plans. The charity Carr Gomm helped me find sheltered accommodation. Susan also found me a great support worker who helped me gather up many of the photos and souvenirs I had of my life and career and compile them into a book of memories that I treasure. For six weeks, I also had some help from a university student called Guillermo from LGBT Health & Wellbeing.

The lifeline from Alzheimer Scotland was critical for me. My family and most of my friends have fallen away since I was diagnosed. There is a lot of stigma surrounding dementia and mental health problems in general. People would phone me up; I'd tell them "I've got dementia" and they'd say "Oh, that's shocking, we'll phone you next week." I'm still waiting for many of those calls from people I counted as friends.

Since my diagnosis I've made a point of trying to fully understand the conditions I now live with. I believe that knowledge is power and that I need to think positively and be accepting of the constraints that dementia has put on my life. I've read as much as I can about my dementia and

listened to lectures by experts from all over the world.

I'm still coming to terms with the limitations that these illnesses have placed on my life. Every day I face an onslaught of symptoms and side effects, both physical and mental. I suffer horrific hallucinations, short term memory loss; sometimes I do not recognise objects or people. They cannot treat my Parkinson's, my body is stiff and I find it difficult to move. I have constipation, various eye problems and a host of other complications. I can't go to the doctors by myself, I can't put my clothes on properly in the morning. I can't work zippers or buttons, my right arm is dead and my left hand is starting to go as well. I can't cook - I can only heat things up in the microwave. One of the doctors said to me quite recently that at some point I have to make a choice between movement and memory. The drugs that will ease my mobility will make my Lewy Body worse.

I've been to a few care homes and it makes me feel very nervous, because I know that that's the last place I want to end up. But eventually I will not be able to do things and even sheltered housing won't be enough. So please indulge me while I paint you a picture of my idea of the perfect sanctuary for a person in my situation:

The most important thing in a care home is the staff. The dream care home would have skilled round the clock nursing staff and carers who are highly trained, knowledgeable and compassionate in their approach to their work.

It should be located in an area that has easy access to public transport, hospitals and amenities. The home should have extensive indoor and outdoor gardens with lots of light and space. Most of the care homes I have visited have been dreary and depressive. A more creative approach to the decor would make life more pleasant for residents. On a practical note, corridors should be spacious and rooms should be larger, with en suite bathrooms that provide lots of room for wheelchair access and space for personal care.

The entrance should be interesting and colourful with an oasis as the central focal point. Common areas should have themed rooms that have visual interest. Furniture should also be practical, comfortable and colourful. Day rooms, a tea lounge, a cinema and television room, a yoga/mindfulness room, arts and crafts room, a music room, dance hall, hairdressers, a library, a gymnasium/activity area and coffee shop should all be built around a glass atrium with an indoor and outdoor garden area.

Residents must have the opportunity to personalise their rooms and see family and friends without time restrictions. There should be more innovation in the kitchens, but still having healthy, nutritious and basic options available which are presented attractively. Meal times should be flexible to suit the residents' desires.

When the architects are designing the building they should be fully aware of the residents' needs and use the latest technology with regard to security, including CCTV and tracker systems. There have been reports in the news that someone has designed a "robotic carer". I personally prefer human carers and see the idea of robotic carers as more of an amusement for residents!

Residents would be offered a wide range of activities, including art classes, jewellery classes, music lessons and therapy, mindfulness classes, alternative and holistic therapies, games and quizzes, dance classes and access to various outdoor activities and trips. Consideration should be taken to fulfil the needs of residents with more eccentric tastes.

The care home could be split into separate wings for people with early onset dementia, older people with dementia and people with other dementia related conditions. Consideration should also be given to LGBTI groups as there should be no discrimination for any minority group, be it sexual, religious or cultural differences. It is essential that more focus is given to the LGBTI community, many of whom feel forced back "in the closet" when they enter a care environment.

In general, there must be something done to make care homes more desirable. It is understandable that there may be budget constraints but it is essential that things change. The government will have to build more care homes, and when they do, let's make them brighter and more attractive places to live.

The best direction to go for in, in my opinion, is to create not only a care home but a "dementia village" like the very successful Hogeweyk Dementia Village in Netherland. This village offers a safe environment for people with dementia, and allows them to live a full and normalised life. They have supermarkets, hairdressers, a cinema, theatres, restaurants and coffee shops. In short, all the things we take for granted until they're taken away...

I have already arranged my own funeral – I lived a stylish life and I intend to go out in style. We British are reluctant to discuss death but I believe it is part of life; it comes to us all. From childhood, I have had what I can only describe as psychic and out of body experiences and those, coupled with coming close to death a couple of times, have made it easier for me to accept the inevitable. The body is, after all, just a shell that houses our soul. I believe, without doubt, in an afterlife, which will be more beautiful than words can describe. Whether you call it Heaven, Paradise, Nirvana or Valhalla, what lies beyond life is not an end but a beginning.

I'd like to leave you with an Aboriginal proverb that is close to my heart:

We are all visitors to this time, this place. We are just passing through. Our purpose here is to observe, to learn, to grow, to love and then... we return home.



Jennifer Hall, Training Officer and LGBT Champion at Alzheimer Scotland explores some of the challenges LGBT people experience when faced with a diagnosis of dementia and explains what Alzheimer Scotland are doing to address this.

At Alzheimer Scotland, we strive towards ensuring our organisation is inclusive and representative of the communities we engage with. If you are lesbian, gay, bisexual and/or transgender (LGBT) we welcome you to our organisation. Whether it be for support, information or advice, or as a volunteer or member, we need your help to ensure that nobody faces dementia alone.

However, there is a lack of awareness and visibility of LGBT lived experience with dementia. With over 90,000 people living with dementia in Scotland we are encountering poor awareness, along with lack of knowledge and information to support this community and their families. It is therefore imperative we make every effort to address the inequalities that exist for this significant minority. We endeavour to ensure our communities become more dementia friendly but this needs to consider the diversity of our society and encompass the needs of the LGBT community.

This is further highlighted in the recommendations set out in *Dementia and Equality – meeting the challenge in Scotland*; a report by the National Advisory Group.

The recommendations call for include:

- a workforce that is informed and open
- safe space is created within supports and services for members of the LGBT community living with dementia
- publicity materials and policy documents are pro-actively inclusive.

There is a growing evidence base that illustrates the lack of understanding and appropriate support for the specific needs of LGBT people living with dementia. *Don't Look Back*, a report produced by the Equality and Human Rights Commission states:

“Older LGBT people have been overlooked in health and social care legislation, policy, research, guidance and practice, which assume service users are heterosexual.”

These uninformed and dangerous assumptions contribute to the fear LGBT people have about being discriminated against within services. This inevitably means individuals are less likely to access services or choose not to come out to service providers when they do.

The LGBT community is often described as “the invisible population” when it comes to dementia care. However, with an estimated 5-7% of our population identifying as LGBT (1 in 15 people), that is a very significant minority when we consider the exclusion and discrimination the LGBT community have experienced both historically and to this day.

LGBT people who have dementia might:

- Not be ‘out’ to their GP & be reluctant to engage with (mental) health services
- Be uncomfortable with care home staff or paid carers knowing about their
- sexual orientation or gender identity – avoid seeking support
- Feel out of place in traditional dementia support groups
- Seeking assistance with personal care particularly difficult for trans people
- Re-experience difficult and distressing times
- Forget that laws and attitudes have changed
- Forget that they are out or have transitioned, or who they are ‘out’ to
- Because of loss of inhibition, be more open in expressing their identity.

LGBT Health and Wellbeing

Prejudice from others can be particularly difficult in these circumstances. It is important that LGBT people and their carers know that services are safe and non-judgemental.

LGBT Health and Wellbeing have made the following recommendations for making services LGBT-inclusive:

- Ensure that staff are informed, open and able to provide culturally appropriate care
- Make sure LGBT people are visibly and pro-actively welcomed and know their confidentiality will be respected
- Have in place workforce development training, which challenges assumptions and increases awareness
- Create a safe space and address issues of prejudice and discrimination, including from other service users.

LGBT Health and Wellbeing also offer the following resources to help make our services more inclusive:

- **Audit Tool:** structured way for services to assess how they are doing and identify ways to keep improving
- **Top Ten Tips:** supporting services to become more LGBT-inclusive
- **Documentary Film:** educational resource for staff and volunteers - with trainers' notes
- **www.lgbthealth.org.uk/online-resources**
- **LGBT Helpline Scotland:** 0300 123 2523 (Tue & Wed 12-9pm)

Alzheimer Scotland LGBT Champions Network

Alzheimer Scotland has established our LGBT Champions network for staff and volunteers across the organisation. Our LGBT Champions are members of Stonewall Scotland Role Models and Allies Alumni who champion positive behaviours, attitudes and terminology and challenge assumptions made about members of the LGBT community. Our goal is to create a culture of comfort and safety, not just for our workforce, but also for LGBT people we engage with across Scotland.

Rainbow Flag Project

Alzheimer Scotland is piloting a Rainbow Flag project within our Glasgow Dementia Resource Centre (DRC). With our DRCs taking dementia to the High Street, this is a great opportunity for us to become more visibly inclusive of the LGBT community. This pilot will give all staff and volunteers based at this DRC the opportunity to participate in a series of LGBT awareness sessions. Once complete we will work alongside people with dementia who use our services to create a rainbow sticker that will be displayed in our windows at the DRC; visibly signifying hope, understanding, empathy and inclusion. By adopting this powerful image, we aim to stimulate conversations about why we are doing this work and the significance of the rainbow for the LGBT community. The intended success of this pilot will be rolled out across our all our DRCs in Scotland.

For further information on our services and support we provide, go to the website www.alzscot.org or phone the Dementia Helpline: 0808 808 3000 (24 hours).



Background

Scotland's population will age over the next 25 years as the 1960s baby boomers reach their 60s and 70s. Between 2016 and 2041, only adults over 65 will increase in number, with those over 75 rising by 79%.¹ Older adults are shown to remain sexually active and enjoy sex into their 70s and beyond.^{2,3} Good health is linked with sexual activity and conversely poor health, which increases with age, is associated with reduced sexual activity and satisfaction.³ A rapidly changing cultural environment since the mid- 20th century has facilitated a more liberal approach to sex, supported by legislation enabling easier divorce, abortion and access to the oral contraceptive pill, as well as increased freedoms for women and men who have sex with men (MSM).⁴ In addition, the importance of lifelong sexual health was recently adopted into UK national sexual health policies.^{5,6} While these cultural and policy shifts represent progress, several factors continue to challenge older adults' sexual health.

Stigma

The public relationship between age and sexuality is controversial. Western privileging of youth links ageing with decay and death.⁷ Societal perceptions, therefore, of age appropriate behaviour limit open discussion and exchange about older adults' sexual health.^{8,9} Relatively recent concepts of ageing well, aiming to extend youthfulness and vitality risk further stigmatisation of ageing bodies by blaming older people for their physical "decline".^{10, 11} Finally, knowledge of older adults' sexuality tends to be heteronormative with very little understanding about what it means to age as an LGBT person.^{11,12}

Life course events

Middle age and beyond is frequently characterised by relationship upheaval. Divorce is highest among those in their 40s, with frequent mid-life re-partnerings.^{13,14,15} Among adults over 45, sexually transmitted infections (STIs) have risen in the last decade; while considerably lower than younger adults, increases in gonorrhoea and chlamydia in England

and gonorrhoea and syphilis in Scotland are recorded among this age group.^{16,17} New diagnoses of HIV among the over 50s have risen to 25% in 2016 from 8% in 2007.¹⁸ Older adults, however, are less likely than young people to use condoms and test for STIs.^{19,20} Problems with sexual function are associated with increasing age; in a large British survey, 27% of men aged 55-74 and 24% of women aged 65-74 reported low sexual function on a scale measuring sexual response, relationship context and self-appraisal of their sex lives.²¹

Key concerns among older heterosexual adults have focussed around erectile dysfunction in men and arousal difficulties in women.² Declining health and mobility may require adaptations to long standing sex lives. Relinquishing sexual expression may be a relief for some but a cause of great loss for others. Among heterosexual older men, sexual potency has been conceptualised as a responsibility for the satisfaction of female partners, central to concepts of masculinity.²² There is evidence, however, of successful adaptation when pleasure is not structured around penetrative phallogentric sex. A wider repertoire of sexual pleasure including communication about sex, mood setting, kissing and touching is associated with increased frequency and sexual satisfaction among mainly heterosexual adults aged 50-85.²³ While older MSM are suggested as better suited to adaptation having had to address their own position relative to cultural norms of masculinity, it is important not to see older minority adults as a homogenous group, as illustrated by challenges experienced by MSM with erectile difficulties.^{22,24} Although many older adults become single through bereavement, divorce and separation, the impact of one person's sexual problem on a partner points to the benefits of addressing sexual problems within relationships.^{2,21}

As older adults' care requirements increase, autonomous sexual expression may become challenged. While recognising that older adults' sexualities are as diverse as the rest of the population, evidence from care home research shows that sexuality in its widest form remains an important part of life for older residents.²⁵ For older adults with dementia, key issues include privacy, capacity to consent, autonomy and protection from harm.²⁶ It is often challenging for carers and families to support sexual expression among older residents. Acknowledgement of challenges, education, including clarity about rights and responsibilities and recognition of diversity are important in addressing the needs of this vulnerable group of adults.^{26,27,28,29}

Health professional/ older client interface

Despite sexual health problems being relatively common in older age, few adults consult health care providers (HCPs).^{9,30} Assumptions that sexual problems are a normal feature of ageing, and embarrassment in raising the subject prohibit help-seeking. According to practitioners, barriers to discussing sex include beliefs that sex among older adults is a private matter, and lack of appropriate training. Evidence suggests that older adults would like HCPs to discuss sexual health with them and HCPs are happy to respond if the older person brings the subject up, however neither are comfortable in raising the topic.⁹ STI related symptoms are often misinterpreted as age-related and risks for HIV and other STIs are overlooked by both older adults and their HCPs.^{31,32}

Knowledge

Very little sexual health promotion targets older adults which reduces opportunities for awareness raising. No large-scale UK based research has assessed older adults' knowledge about sexual health issues, including STIs, and there are no published evaluations of any UK based intervention programmes targeting older adults. Growing up in a gendered and stigmatised environment is likely to have influenced older adults' current understandings of STIs and HIV.^{33,34} Although few older heterosexual adults reported searching for STI-related information, those who did found TV and magazines the most popular source, while HCPs were the most trusted, further highlighting the need to challenge practitioner/patient barriers.^{32,35}

The way forward

Addressing the complexity of barriers to sexual health faced by older adults necessitates multi-faceted intervention. Hinchliff and Barrett outline a rights-based approach to older adults' sexuality, focusing on raising awareness, recognition of older adults' sexual rights at policy level and addressing inequalities.³⁶ Specific needs of older adults who are in sexual minorities should be highlighted as a vulnerable and much overlooked group. In addition, education involving older adults themselves, carers and families, health care professionals and the wider public should be prioritised in seeking to bring down barriers and reduce stigmas by promoting open discussion of sexual health issues that are relevant to the older population.



Clive Blowes, HIV and ageing lead at Terrence Higgins Trust, shares the results of the charity's recent research into the experiences of older people living with HIV in the UK.

The success of modern HIV treatment now means that people living with the virus can expect to live a full life expectancy. As a result, we are now seeing the first generation of people growing older with HIV.

But are our health and social care services ready? Because they need to be – and quickly. Older people are the fastest growing group of people living with HIV in the UK. New diagnoses of HIV in the over 50s continue to increase. The proportion of new diagnoses in the over 50s in Scotland has risen dramatically from 7% in 2007 to 25% in 2016. In Scotland, as in the rest of the UK, nearly four in ten people living with HIV are over the age of 50. That number is estimated to increase still further, reaching 54% by 2028.

Last year, Terrence Higgins Trust published a pioneering report into the first generation of people with HIV growing older, titled '*Uncharted Territory*'. This report, produced by peer researchers - a team of volunteers living with HIV in the UK aged 50 and over - was designed to give an insight into the experience of what it is like to grow older with HIV, and the challenges they face.

Older people living with HIV are often managing a number of other conditions, including cardiovascular problems, kidney problems, osteoporosis and diabetes. The over 50s living with HIV in our report had on average three times as many long-term health conditions compared with the general population. In particular, those who were diagnosed before the introduction of combination therapy in 1996 were more likely to have three or more conditions. Additionally, survey respondents reported lower levels of wellbeing with increasing numbers of co-morbidities and increasing numbers of daily medications needed.

Many people reported that they were already struggling to remember to take multiple medications, as well as remember the multiple healthcare appointments their health conditions necessitated. Nearly 8 out of 10 (79%) were concerned about memory loss and cognitive impairment in the future and how they would cope with managing multiple health conditions. People were concerned about how they would take care of themselves

and manage daily tasks in the future. Our study showed that a quarter of respondents said they would have no one to help them if they ever needed support with daily tasks.

A fundamental concern that was highlighted in the research was the fear that individuals would not be able to access social care – that financial barriers would prevent them being able to afford the care that they need. Altogether, 82% of over 50s living with HIV were concerned about whether they would be able to access adequate social care in the future and 88% had not made any financial plans to fund future care needs. There was a feeling of lack of agency and control over future social care and support, with a lack of financial freedom limiting (or eliminating entirely) their ability to choose a residential care setting.

Even where people living with HIV have been able to access social care services, they have faced discrimination from care professionals due to their HIV status, including in residential care homes. Research participants who had direct experience of social care reported a gross lack of understanding and awareness of HIV among social care professionals – particularly around confidentiality. One participant had their HIV status revealed to their brother when somebody delivering mobility equipment left a document mentioning the participant's HIV status visible. This led to the end of that important relationship. Another participant had their HIV status revealed to a friend when a home care support worker mentioned their HIV status in conversation in front of them.

Similarly, other cases demonstrated that procedures around caring for someone living with HIV have not been updated since the outbreak of the epidemic. A resident in a care home in London was encouraged to spend as much time in their room as possible to avoid contact with other residents. If the individual did sit in the resident's lounge, they were only allowed on one particular chair. The TV remote control was taken away when they tried to use it and wiped down with antibacterial wipes. Care staff were told to 'double glove' when changing the bedding.

Understandably, cases such as these lead to concerns for the future for individuals as they age with HIV. Research respondents who do not currently access social care, but who foresee that they will have to in the future, reported concerns with staff not knowing how to care for someone with HIV. For LGBT people, there was also concern they would have to go back into the closet about their sexual orientation because they may experience stigma and homophobia from other residents. Discrimination from staff could also lead to poorer quality care. However, it should be

noted that discrimination does not usually come from malice but because of a lack of up to date information and knowledge on what it means to live with HIV today.

That's why we've launched our Terrence Higgins Trust Learning Centre, to provide high quality HIV and sexual health training. Based in the centre of Glasgow, our training ensures everyone who attends finds out the facts about HIV – including that you can't get HIV from day-to-day contact and there's absolutely no need to treat someone with HIV differently. Medically, things have changed a great deal since the early days of the epidemic, but – in terms of stigma and misinformation – we still have a long way to go. Brilliantly, we see many healthcare professionals on our courses, several of which are accredited by the Scottish Qualifications Authority. This means we're working towards a day when people living with HIV don't have to worry about disclosing their status to healthcare professionals. There should be no difference in the treatment of people living with HIV who are being cared for in their home or in a residential setting. Standard precautions are all that are necessary when caring for someone living with HIV. HIV is predominantly passed on through sexual contact and the vast majority of people on treatment today have an undetectable level of the virus, which means that they are unable to pass on HIV.

It is important to remember that the first generation of older people living with HIV are a diverse group with a wide range of experiences. While many will continue to live without the need for additional health and social care services or financial support, there is a major cohort of individuals growing older with HIV who will require significant levels of support, both now and in the future.

Of course, a number of these support needs are not unique to people living with HIV – the welfare and social care systems across the UK are failing many. However, we have found that living with HIV adds an extra level of need – additional necessities that go beyond the 'standard' experiences of ageing. Therefore, it is important that the care sector has up-to-date knowledge and is ready to respond to these needs in the years ahead.

For more information about Terrence Higgins Trust's training courses, visit tht.org.uk or call 0141 332 3838. For more about support available for older people living with HIV, visit tht.org.uk/hwh

A Final Word

Nine years on from the publication of Scotland's first national Dementia Strategy we have continued to demonstrate our commitment to transforming services and improving outcomes for people living with dementia and their families. With a drive to increase diagnosis rates in Scotland and a strong focus on post diagnostic support there is increased awareness and understanding of the nature and experience of dementia, reduced stigma, a strong focus on living well and the fulfilment of rights for people living with dementia. However, we are still encountering a lack of confidence, poor understanding and appreciation of the part sexuality must play in our lives.

We know from conversations and feedback that practitioners can find the very definition of sexuality overwhelming, it is after all an all-encompassing diverse term. But what does this mean for individuals living with dementia and how does our knowledge and understanding of sexuality translate into our practice?

This Care Cameo is not intended to hold all the answers, in fact, it will probably raise more questions. The topic of sexuality and dementia poses not only opportunity but also layers of complex ethical and moral dilemmas. It is merely an invitation to start a conversation and deepen our understanding of some of the key issues identified so far and contribute to the wider human rights debate. Sexual rights are human rights and with our duty of care comes our duty to consider how we encompass this part of an individual's identity in the support people need to live their lives.



References

1. National Records of Scotland (2017) Projected Population of Scotland (2016 based). Available at: <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/population-projections-scotland/2016-based>
2. Lee, D., Nazroo, J., O'Connor, D., Blake, M. and Pendleton, N. (2016) Sexual health and well-being among older men and women in England: findings from the English longitudinal study of ageing, Archives of Sexual Behavior 45(1),133-144
3. Field, N., Mercer, C., Sonnenberg, P., Tanton, C., Clifton, S. et al (2013) Associations between health and sexual lifestyles in Britain: findings from the third national survey of sexual attitudes and lifestyles (NATSAL-3), The Lancet, 382, 1830-1844
4. Weeks, J. (2007) The world we have won. London: Routledge
5. Scottish Government (2015) Sexual Health and Blood Borne Virus Framework 2015-2020 Update. Available at: <http://www.gov.scot/Resource/0048/00484414.pdf>
6. Department of Health (2013) A framework for sexual health improvement in England (online) Department of Health. Available at: <http://www.gov.uk/government/publications/a-framework-for-sexual-health-improvement-in-england>
7. Nelson (2011) Ageism: the strange case of prejudice against the older you. In: Wiener, R., Willborn, S. Disability and aging discrimination: perspectives in law and psychology. Lincoln, USA: Springer
8. Backett, K., Davison C (1995). Lifecourse and lifestyle: The social and cultural location of health behaviours, Social Science and Medicine, 40, 629-638
9. Hinchliff, S. and Gott, M. (2011) Seeking medical help for sexual concerns in mid- and later life: a review of the literature, Journal of Sex Research, 48, 106-117
10. Marshall, B. (2011) The graying of "sexual health": a critical research agenda, Canadian Review of Sociology, 48, 390-413
11. Westwood, S. and Lowe, J. (2018) The hidden sexualities of older lesbians and bisexual women. In: Barrett C., Hinchliff S. Addressing the sexual rights of older people, theory, policy and practice, London: Routledge
12. Cook-Daniels, L. and Munson, M. (2018) Transgender older people: at sea far from the sexual rights shore In: Barrett C., Hinchliff S. Addressing the sexual rights of older people, theory, policy and practice, London : Routledge
13. Office for National Statistics (2017) Divorces in England

and Wales ²⁰¹⁶. Available at: <https://www.ons.gov.uk/releases/divorcesinenglandandwales2016>

14. Scottish Government (2017) Civil Justice Statistics in Scotland 2015-16. Available at: <http://www.gov.scot/Resource/0051/00515767.pdf>
15. Mercer, C., Tanton, C., Prah, P., Erens, B., Sonnenberg, P. et al (2013) Changes in sexual attitudes and lifestyles in Britain through the life course and over time: findings from the national surveys of sexual attitudes and lifestyles (NATSAL), *The Lancet*, 382, 1781-1794
16. Public Health England (2017) Table 2: new STI diagnoses and rates by gender, sexual risk and age group 2012-2016. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/626361/2016_Table_2_Selected_STI_diagnoses_rates_by_gender_sexual_risk_age_group.pdf
17. Health protection Scotland (2017) Genital chlamydia and gonorrhoea infection in Scotland: laboratory diagnoses 2007-2016. Available at: <http://www.hps.scot.nhs.uk/bbvsti/index.aspx>
18. Health Protection Scotland (2017) Blood borne viruses and sexually transmitted infections, Scotland 2017. Available at: <http://www.hps.scot.nhs.uk/resourcedocument.aspx?id=6305>
19. De Visser, R., Badcock, P., Rissel, C., Richters, J., Smith, A et al (2014) Safer sex and condom use: findings from the second Australian study of health and relationships, *Sexual Health*, 11, 495-504
20. Grulich, A., de Visser, R., Badcock, P., Smith, A., Richters, J. et al (2014) Knowledge about and experience of sexually transmissible infections in a representative sample of adults: the second Australian study of health and relationships. *Sexual Health*, 11, 5, 481-494
21. Mitchell, K.R., Mercer, C.H., Ploubidis, G., Jones, K.G., Datta, J. et al (2013) Sexual function in Britain: findings from the third national survey of sexual attitudes and lifestyles (NATSAL-3), *The Lancet*, 382, 1817-1829
22. Kristiansen H. and Sandberg L. (2018) Older men's experience of sexuality and their relevance for sexual rights. In: Barrett, C., Hinchliff, S. Addressing the sexual rights of older people, theory, policy and practice, London: Routledge
23. Gillespie, B. (2017) Correlates of sex frequency and sexual satisfaction among partnered older adults, *Journal of Sex and Marital Therapy*, 43, 403-423
24. Jowett, A., Peel, E. and Shaw, R. (2012) Sex and diabetes: a thematic analysis of gay and bisexual men's accounts, *Journal of Health Psychology*, 17, 409-418
25. Mahieu, L. and Gastmans, C. (2015). Older residents' perspectives on aged sexuality in institutionalized elderly care: a systematic literature review, *International Journal of Nursing Studies*, 52, 1891-1905

26. Mental welfare commission for Scotland (2011) Consenting adults? Guidance for professionals and carers when considering rights and risks in sexual relationships involving people with a mental disorder. Available at: http://www.mwcscot.org.uk/media/51782/updated_consenting_adults.pdf
27. Di Napoli, E., Breland, G., and Allen, R. (2013) Staff knowledge and perceptions of sexuality and dementia of older adults in nursing homes, *Journal of Aging and Health*, 25, 1087-1105
28. Ward, R., Vass, A., Aggarwal, N., Garfield, C. and Cybyk, B. (2005). A kiss is still a kiss? The construction of sexuality in dementia care, *Dementia*, 4, 49-72
29. Bauer, M., Nay, R., Tarzia, L., Fetherstonhaugh, D., Wellman, D. et al (2014) 'We need to know what's going on': views of family members toward the sexual expression of people with dementia in residential aged care, *Dementia*, 13, 571-585
30. Hinchliff, S., Tetley, J., Lee, D. and Nazroo, J. (2017) Older adults' experiences of sexual difficulties: qualitative findings from the English longitudinal study on ageing (ELSA), *The Journal of Sex Research*, 55:2, 152-163
31. Durvasula, R. (2014) HIV/AIDS in older women: unique challenges, unmet needs. *Behavioral Medicine*, 40, 85-98
32. Slinkard, M. and Kazer, M. (2011) Older adults and HIV and STI screening: the patient perspective, *Geriatric Nursing*, 32, 341-349
33. Dalrymple, J., Booth, J., Flowers, P., Hinchliff, S. and Lorimer, K. (2016) Socio-cultural influences upon knowledge of sexually transmitted infections: a qualitative study with heterosexual middle-aged adults in Scotland, *Reproductive Health Matters*, 24, 34-42
34. Fileborn, B., Brown, G., Lyons, A., Hinchliff, S., Heywood, W. et al (2018) Safer sex in later life: qualitative interviews with older Australians on their understandings and practices of safer sex, *The Journal of Sex Research*, 55, 2, 164-177
35. Lyons, A., Mikolajczak, G., Heywood, W., Fileborn, B., Minichiello, V. et al (2018) Sources of information-seeking on sexually transmitted infections and safer sex by older heterosexual Australian men and women, *Educational Gerontology*. Available at: <https://doi.org/10.1080/03601277.2018.1433989>
36. Hinchliff, S. and Barrett, C. (2018) Moving forward, implementing change. In : Barrett C., Hinchliff S. *Addressing the sexual rights of older people, theory, policy and practice*, London: Routledge



Scottish Care
Voice of the independent care sector