



## **Proceedings of the Policy and Practice Forum on Gender and Dementia Care: Aspects of Family Caring**

**6 October 2021**

# Contents

<b>Section</b>	<b>Page No.</b>
<b>1.0 Introduction</b>	3
<b>2.0 Key Themes</b>	3
2.1 <i>Importance of kin relationships and portrayal of family carers of people with dementia in gender neutral terms</i>	3
2.2 <i>Gender differences in the caregiving experience</i>	4
2.3 <i>Male family carers – invisibility, stigma and varied evidences</i>	5
2.4 <i>Family carers from LGBTQI+ community – commonalities and differences</i>	6
2.5 <i>Family carers of people with dementia – an intersectional approach</i>	7
2.6 <i>Implications for policymakers, service providers and researchers</i>	8
<b>3.0 Opening Address</b>	10
3.1 <i>Janette Dwyer, Assistant National Director, Services for Older People and Dementia Care, Change and Innovation, HSE</i>	10
<b>4.0 Summary of Presentations</b>	12
4.1 <i>Dr Nikki Dunne, Research Officer, Family Carers Ireland</i>	12
4.2 <i>Zoe Hughes, Senior Policy and Research Officer, Care Alliance Ireland</i>	14
4.3 <i>Dr Maria Pertl, Lecturer in Psychology, RCSI, and DRNI member</i>	16
4.4 <i>Paddy Crosbie, family carer, in conversation with Dr Laura O’Philbin, The Alzheimer Society of Ireland</i>	18
<b>5.0 Panel Discussion</b>	20
<b>6.0 Further Information</b>	25
<b>7.0 About the Organisers</b>	25
<b>8.0 Speaker Biographies</b>	26
References	29
Abbreviations	31

Report prepared by Dr. Maria Pierce

*In memory of Derek Simpson*  
*June 1953 – November 2021*

## 1.0 Introduction

It is estimated that there are currently 64,000 people living with dementia in Ireland. Family carers provide the bulk of care to people with dementia and it is estimated that there are more than 60,000 family carers providing care to people with dementia in Ireland. While caring can be rewarding, family carers can experience a myriad of challenges including social isolation and loneliness, mental health difficulties and negative physical health (Care Alliance Ireland, 2020). Family carers, who are more often women, are also more likely than the general population to live in poverty, with many family carers experiencing a sharp decrease in their earning ability.

The feminisation of caring, as well as the lack of status and recognition for caring activities, has resulted in many male family carers feeling stigma, which can lead to a reluctance to ask for or accept help (Care Alliance Ireland, 2020). For minority groups, such as carers from the LGBTQI+ community, these effects are likely to be compounded by other issues connected with their minority status, which they have may been experiencing before the onset of caring responsibilities.

A Policy and Practice Forum was hosted by Dementia Research Network Ireland (DRNI) and the National Dementia Office (NDO) on 6<sup>th</sup> October 2021, as part of the Engaging Dementia 13<sup>th</sup> International Dementia Conference. The aim of the forum was to raise awareness of inequity facing female family carers as well as the lack of visibility, research and support for male family carers and family carers from the LGBTQI+ community.

The forum began with a welcome by **Dr. Carol Rogan**, Scientific Project Manager, DRNI who welcomed the participants on behalf of DRNI and the NDO. Carol thanked Engaging Dementia for hosting the forum as part of its 13<sup>th</sup> International Dementia Conference before outlining the forum's programme. The welcome from DRNI was followed by an opening address given by Janette Dwyer, Assistant National Director, Services for Older People and Dementia Care, Change and Innovation, HSE. This was followed by a session on The Family Care Landscape on Dementia Through a Gender Lens (Section 4). A panel discussion exploring issues around the LGBTQI+ community and dementia care then took place (Section 5).

## 2.0 Key themes

Below are key themes from the forum.

### **2.1 Importance of kin relationships and portrayal of family carers of people with dementia in gender neutral terms**

It is not unusual to think and talk about family carers providing care to people with dementia in terms of their kin relationships. For example, the Irish National Dementia Strategy refers to family carers according to their relationship with the person with dementia to whom they are providing care, e.g., as adult children and spouses (Department of Health, 2014). Kin relationships are important in dementia care. Caring is usually understood as a reflection of long-standing family relationships, and this applies both to relationships by marriage and by blood (Greenwood and Smith, 2019). Most frequently, it is spouses and adult children who take on the role of family carer for a person with dementia. The forum included a contribution

from Paddy Crosbie, a spousal carer, who in conversation with Laura O’Philbin spoke about his marriage and relationship to Derek, his experience of supporting and providing care since Derek developed younger onset dementia, the emotional bonds between them and reciprocal motivation for caring. For her presentation, Dr Maria Pertl drew on findings from the De-Stress study, the largest study conducted in Ireland of spousal family carers of people with dementia. The experiences of adult children as family carers to people with dementia and how it impacts on them are also important.

While the kinship relationships in family caring are often acknowledged and recognised, family carers are generally portrayed in gender neutral terms. For example, the gender of family carers is neglected in the Irish National Dementia Strategy. While, many participants in research on family caring in dementia are women, reflecting the predominance of women as providers of informal care, research on the gendered nature of family caring in dementia care in the Irish literature is limited, as it is internationally (Bartlett, Gjernes, Lotheringon & Obstfelder, 2018). In this context, the Forum provided speakers with an opportunity to bring to the fore gender aspects of family caring in dementia. The gendered nature of family caring in the context of dementia was acknowledged and gendered assumptions underpinning this care, and how it impacts family caring, were considered. Data on family carers of people with dementia, analysed using a gender lens, were presented. The policy and practice implications for health and social care service provision as well as social welfare services were highlighted.

The portrayal of family carers in sexuality blind terms, which was also a key theme of the forum, is addressed in section 2.5.

## **2.2 Gender differences in the caregiving experience**

In an attempt to address gender neutral portrayals of family carers, speakers at the Forum drew attention to differences between men and women providing care to family members with dementia, highlighting several significant differences. Women more often than men provide informal care, as evidenced in Ireland by Irish census data and the Irish Health Survey. Women are the predominant providers of informal care, including to people with dementia, not only in Ireland but worldwide (WHO, 2012). Up to three-quarters of family carers of people with dementia are women (Bamford, 2011). As well as more often providing care, women tend to provide more intense levels of care. Speakers pointed to the historical, societal and cultural demands on women to adopt the role of family carer, including for people with dementia.

Caregiving can be rewarding and there are positive aspects to providing care to people with dementia. However, there is extensive evidence showing that caring for a person with dementia can be demanding for family carers, both physically and psychologically. Surveys such as those undertaken by Family Carers Ireland point to the negative impacts on the physical health and mental wellbeing of family carers of people with dementia. There are also financial implications, which can have long-term effects. Given that the majority of family carers of people with dementia are women, women are disproportionately impacted. The De-Stress study, although not designed as a gender focused study, offers useful findings on differences between male and female spousal carers of people with dementia in relation to caregiver health and wellbeing in Ireland. The study found that being a male spousal carer to people with dementia was a marker of having greater supports and of being more confident in accessing support and responding to dementia. Male spousal carers also fared better than female spousal carers in terms of their psychological wellbeing. They had lower levels of

depression, anxiety, caregiver burden, stress and loneliness, and their sleep quality was better. They reported better life satisfaction, higher quality of life and identified more positive aspects associated with providing care such as personal growth, making connections or learning new skills. Many of these findings are consistent with studies focusing on gender differences in the caregiving role in dementia from other countries (Bartlett et al., 2018).

The findings highlight that gender affects the caregiving role in dementia care. As Bartlett et al. (2018) point out, findings such as these provide valuable evidence of how gender differences matter in the context of dementia care. Dr Pertl offered a number of explanations for the findings from the De-Stress study including the socialisation of women as carers, societal assumptions about gender roles and men's acculturation to stigma related to mental health difficulties, highlighting the importance of addressing wider gender inequalities and issues in Irish society.

### **2.3 Male family carers - invisibility, stigma and varied experiences**

While female family carers outnumber male family carers across all age groups, male family carers still clearly provide a significant amount of unpaid care. Nevertheless, because most family carers including those providing care to people with dementia are women and because of the feminisation of care work, there is a risk that male family carers become invisible. There is also a risk that male family carers are stigmatised, due to the tension between being a male and being a family carer. This may suggest that there needs to be a greater focus on male family carers in dementia care research. However, Bartlett et al. (2018) found that a relatively high proportion of studies on gender differences in relation to dementia caregiving are from a male caregiver perspective, underscoring the need to consider gender as it influences all family carers by researchers as well as by policymakers and service providers. More research directly comparing male and female carers is needed (Greenwood and Smith, 2015).

Speakers pointed to the contradictory nature of the evidence reported on male family carers at the forum. On the one hand, for example, it is suggested that men are less likely to self-identify as a family carer, a consequence of which is that male family carers are less likely to access support. On the other hand, a finding of the De-Stress study is that male spousal carers of people with dementia have greater access to support than their female counterparts. Mixed evidence relating to male family carers' access to support, both generally and specifically in relation to dementia care, has been noted elsewhere (Bartlett et al, 2018, Greenwood and Smith, 2015; Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014) and is likely to be a sign that there are variations in the experiences of male family carers (Bartlett et al, 2018). This reminds us that male family carers of people with dementia are not one homogenous group of people. It was suggested that a masculinities framework may be useful for informing our understanding of the relationship between male caregivers and their carees. An example of the masculinities framework is that offered by Hanlon (2009), which posits three categories of men/masculinities at work in caregiving (i.e., conventional masculinities, sharing masculinities and caring masculinities), (Robinson et al., 2014).

While traditional gender roles are changing, currently, a minority of formal care workers are male. The implications of this were highlighted at the forum. For example, a man with dementia and his family carer may request a male carer when expressing a preference for who is assigned to look after them, but with so few formal male carers, it may be difficult for services to satisfy this request. Personhood is a guiding principle of the National Dementia Strategy

and the NDO's new Model of Dementia Care is guided by a personalised approach. This means that care is to be tailored to the preferences and needs of people with dementia and their family carers. However, until more men move into the professional carer space, the difficulty in satisfying a preference for a male carer will remain.

#### **2.4 Family carers from LGBTQI+ community – commonalities and differences**

It is estimated that there are more than 60,000 family carers of people with dementia in Ireland (Pierce, Cahill and Carney, 2017) and the valuable contribution they make to Irish society was acknowledged at the forum. However, there are no reliable statistics on the number of family carers that are LGBTQI+ or estimates of the contributions that they make to society through their caring role.

As exemplified by Paddy's contribution, family carers from the LGBTQI+ community share many common experiences and concerns with those in the wider population of family carers of people with dementia. They want the personhood of people with dementia to whom they are providing care to be promoted and they want a strength-based approach adopted. They want individualised care that is tailored to the needs of the person with dementia to whom they are providing care and they want continuity of care. They emphasise the importance of relationships in the provision of care to people with dementia and want to work in partnership and develop trusting relationships with formal care providers, to deliver care agreed between all concerned – caree, family carer(s) and formal carers – to support people with dementia to live a valued and dignified life.

At the same time, providing care as an LGBTQI+ person to a family member with dementia can bring particular aspects and challenges, both for the person caring and the caree. For example, Paddy Crosbie spoke about the worries that people from the LGBTQI+ community may have when seeking out supports because of negative attitudes towards them and prejudice and discrimination that they may experience because of their sexual orientation. Past experiences of older family carers in the LGBTQI+ community may be particularly negative, because of discriminatory laws that were in place when they were younger, and this may influence the need they feel to hide their sexual identity and how they cope in their everyday lives. It is reassuring to hear that when supports were sought, Paddy's worries did not materialise. It reflects a readiness on the part of the dementia services in which he engaged to recognise, understand and meet the needs of LGBTQI+ people with dementia and of their family carers. However, we will not know how common this is until we hear from more family carers in the LGBTQI+ community, including LGBTQI+ adult children providing care to a parent, about their experiences and have a better understanding of this from research. Assumptions of heterosexuality among health and social care staff is another issue for some family carers from the LGBTQI+ community, who may feel uncomfortable about being open about their sexual orientation around health and social professionals, or having to 'come out' repeatedly, especially if it is not known how their sexuality will be perceived, interpreted and responded to.

In Ireland there is a tendency to rely on family as the primary provider of care to people with dementia. The question of 'what is family?' becomes an increasingly important policy concern when the distinct situation of people with dementia and/or family carers from the LGBTQI+ community are considered. Older LGBTQI+ people are less likely to have a spouse or partner and less likely to have children or grandchildren to support them. They are also more likely to

be living alone. Some LGBTQI+ people may not see their family of origin regularly or at all and/or prefer to involve and be supported by people who support them as family but are not members of their family of origin. The concept of 'family of choice' is therefore important in dementia care and caring generally. Informal carers of LGBTQI+ people with dementia tend to be of a similar age. The unique social networks in which LGBTQI+ family carers find themselves highlights the need for an inclusive definition of family in dementia care that recognises family pluralism and diversity, or perhaps it may be more apt to use the term social network or support when discussing informal care and dementia.

Paddy mentioned the fact that he and Derek have never met another gay couple living with dementia, highlighting just how invisible people with dementia and family carers from the LGBTQI+ community are in Irish society. This is despite research from the US suggesting that LGBT people become caregivers at a higher rate than the general population (AARP and National Alliance for Caregiving, 2015).

There was a consensus at the forum that sexual orientation of family carers is often overlooked, leading to the criticism that policy and services are sexuality-blind. Sexuality blindness can be defined as the invisibility, devaluation and/or denigration of the romantic lives of LGBTQI+ individuals. It serves to disregard and invalidate an individual's identity-related experiences (Holmes, 2020). None of the speakers could see any advantage in adopting a sexuality-blind approach to the provision of services to people with dementia and their family carers. It was argued that a health inequities perspective could rather be taken, whereby inequities between LGBTQI+ and other family carers can be understood through the lens of health determinants.

## **2.5 Family carers of people with dementia: an intersectional approach**

At the forum, different groups of family carers of people with dementia were discussed. While family carers may be categorised into groups such as female family carers, male family carers and LGBTQI+ family carers, it was recognised that a person's identity, including that of a family carer and a person with dementia, is complex. In addition to gender and sexual orientation, age was also identified as a factor structuring a person's unique experience and identity. In speaking about Derek, Paddy illustrated how the experience of a gay man with younger onset dementia could be structured by each of these identities. As a gay man, he might be hesitant to seek out supports for fear of experiencing prejudice or discrimination. As a person with younger-onset dementia, dementia-specific services, which are generally designed for and attended by older people with dementia and their family carers, may be experienced as being less relevant or not age-appropriate. As a man with dementia, he may prefer to receive formal care from a male carer, but this might prove difficult to arrange as only a minority of formal care workers are men.

The concept of multiple identities is a useful concept for reflecting the complexity of people's social identity (Fraser, 2000) and can be applied to family carers. It is useful for not only highlighting differences among family carers, but also highlighting diversity among sub-groups of family carers. For example, male carers include those who identify as heterosexual and those that identify as non-heterosexual. The term 'LGBTQI+ family carers' acknowledges the diverse range of sexual identities and gender expressions among family carers, but their experience may also be structured by kin relationship to a person with dementia and age, for example. Other factors making up the identity of family carer such as ethnicity, disability or

socio-economic status were cursorily mentioned at the forum. The idea of multiple identities helps to surface new and varied views of family carers and can help to capture the diversity of experiences of family carers of people with dementia. However, people with multiple identities experience acute prejudicial attitudes and disrespect and face multiple barriers to equality, as has been documented by Zappone (2003).

As well as highlighting diversity among family carers, an intersectional approach can also highlight commonalities among family carers. A common issue facing family carers (as well as people with dementia and people generally) as they age that was discussed at the forum is the way in which society desexualises older people, irrespective of their gender or sexual orientation. It does not recognise that many people, including family carers, remain sexually active across the lifespan or the ways in which people wish to express their sexuality in later life such as through dress.

## **2.6 Implications / messages for policymakers and service providers**

We have a habit in Ireland of treating groups such as older people, people with dementia and family carers of older people and people with dementia as one homogenous group of people. While family carers share common experiences and concerns, this Forum has shown that family carers of people with dementia are also characterised by diversity. It highlights how men and women experience and are impacted by family caring differently. Likewise, family carers from the LGBTQI+ community experience and are impacted differently. A key message from the Forum is that gender and sexuality matter. There is a need to move away from gender-neutral and sexuality-blind policies and services and to move towards gender- and sexuality-sensitive policies and services in order to promote equality between women and men and for family carers from the LGBTQI+ community. There is a need to address structural inequalities that exist. Other factors influencing a person's identity such as age, ethnicity, disability, socio-economic status and so on also matter. It is no longer sufficient to develop policies and services that promote great support for a homogenous grouping of family carers. Addressing issues raised in this Forum could begin with mainstreaming diversity in the Irish National Dementia Strategy with respect to both people with dementia and family carers.

Speakers pointed to the assumptions about gender, sexuality, age, etc that need to be challenged. For example, family carers, like everyone, will have a gender identity (how they see themselves – male, female, both or neither). It is important never to make assumptions about these.

While creating a plethora of services to meet the needs of different groups of people with dementia and their family carers is not recommended, a proactive approach needs to be taken by all service planners and providers to achieving equality and tailoring services to meet the particular needs of diverse family carers within services. Equality training for health service professionals needs to draw attention to the fact that family carers are diverse. Organisations need to be equality competent and foster a culture that values diversity, including of people with dementia and their family carers. There is much to be learned from programmes and projects already underway in Ireland such as the LGBT Champions Programme (<https://lgbt.ie/champions-programme/>) and at EU level such as BEING ME (<https://beingme.eu/project>). Critically, all public bodies in Ireland have responsibility to promote equality, protect the human rights of service users and everyone affected by their

policies and plans. This is referred to as the public sector equality and human rights duty, a legal obligation that originated in the Irish Human Rights and Equality Act, 2014.

Findings from studies on differences between male and female family carers of people with dementia can be used to inform and develop suitable interventions to support the physical, psychological and financial welling of male and female family carers. More data and evidence are needed on LGBTQI+ people and their experiences as family carers of people with dementia. While attention has been paid in Ireland to tailoring services to the individual needs of people with dementia and their family carers generally, limited attention has been paid to the perspective of LGBTQI+ people.

Organisations can ensure that family carers from a diversity of backgrounds and a range of identities are involved in policymaking, service planning and research.

## 3.0 Opening Address

### 3.1 Janette Dwyer, Assistant National Director, Services for Older People and Dementia Care, Change and Innovation, HSE

**Janette Dwyer** expressed her delight at being invited to open the Policy and Practice Forum and thanked the DRNI and the HSE's NDO for organising and co-hosting the event. The focus of this second co-hosted Policy and Practice Forum is on the gendered nature of dementia care-giving and key considerations related to the role of female carers, the invisibility of male family carers and the emerging issues for people who are both members of the LGBTQI+ community and providing care to family members. It is estimated that in Ireland there are over 64,000 people living with dementia and this number is expected to rise to over 150,000 by 2045 if current trends persist (Health Atlas Ireland, 2020). Dementia has physical, psychological, social and economic impacts not only for people living with dementia, but also for their carers, families and society at large. Dementia is a condition that is not only experienced by older people; there are approximately 4,000 people under 65 years of age living with dementia. Globally, dementia is currently ranked as the 5<sup>th</sup> leading cause of death and is one of the major causes of disability and dependency among older people. Increasingly, more is known about the risks associated with developing dementia and some groups, e.g., people with intellectual disability, are at a greater risk of developing dementia.

Key issues in dementia care need to be addressed. Dementia diagnostic rates need to be improved; it's estimated that currently only 40% of people with dementia receive a formal diagnosis. The lack of awareness and understanding of dementia that often exists can lead to stigmatisation of dementia resulting in barriers to getting a dementia diagnosis and appropriate care.

Dementia Understand Together is the key national dementia awareness programme aimed at addressing stigma surrounding dementia, increasing understanding of the condition and supporting and helping people living with dementia by working towards the development of dementia-inclusive communities.

Family carers play a vital role in supporting people with dementia. People with dementia are high users of health services. It is estimated that 37% of recipients of home care services are people with dementia and up to 30% of people admitted to acute hospital are living with dementia. People with dementia admitted to hospital have longer hospital stays and a higher risk of mortality in that setting. A high proportion of people in long-stay residential care are people with dementia. However, family carers who provide the bulk of care are often the most important resource for people with dementia and given their important role should not be overlooked. Family carers continue to provide care and support to people with dementia who are admitted to hospital or who are resident in a long-stay residential care setting. While it is not easy to place a monetary value on family caring, the World Health Organization (WHO) estimates that 50% of the global cost of dementia care can be attributed to informal caring.

Later in the forum, presenters will speak about the family carer role and the gendered nature of that role. Family caring differs depending on a number of factors such as the relationship between the family carer and the person with dementia and can be affected by the physical,

social and support environment in which the family carer is living. Services such as day care, home care, restorative care and respite can be important in supporting family carers to continue in their caregiving role. It is very important to highlight the Covid-19 pandemic and the challenges it poses for family carers and people with dementia, especially with the pausing of many formal supports. Thankfully, progress is being made with phased opening of day care services, but it is still important to acknowledge the impact that the temporary closure of services has had on people with dementia and their family carers.

Government policy is to support people to live at home for as long as possible and, Janette, stressed that her focus, as the Assistant National Director for Services for Older People, Change and Innovation, is on reforming services for all older people with a view to enabling people to live at home for as long as possible including people with dementia. Across the broad spectrum of service delivery, the focus is on enabling people to live in their home setting for as long as possible through the provision of supports for them and their families. Under the HSE's National Service Plan, a number of organisations such as the Alzheimer Society of Ireland (ASI) have been funded to continue with the provision of daily support at home. This has been of great importance during the Covid-19 pandemic, when day care services were closed, as it helped to provide some respite for family carers. A national Dementia Adviser service is operating across the country, with Dementia Advisers offering information, advice, signposting and emotional support directly to people with dementia and to their families. A network of Memory Technology Resource Rooms (MTRRs) has been established across the country supporting family carers through the provision of information and advice on assistive technology as well as practical information and advice on how to manage and cope day-to-day with dementia. With respect to future plans for dementia care, the HSE will continue to strive to improve services for people with dementia. As part of its plan for improvement, a Dementia Model of Care is in development and currently being finalised. The Dementia Model of Care has been informed by available evidence, and through consultation with key interest groups and stakeholders including people living with dementia and their family carers. As part of the consultation process, the NDO recently met with the Irish Dementia Working Group (IDWG) and the Dementia Carers Campaign Network (DCCN) to ensure that people with dementia and their family carers have their voices heard and are given the opportunity to input into the development of this important model of care. The public consultation on the model has recently closed and, using the submissions, the NDO is working on revising the model, which will be issued shortly.

Janette once again thanked Dr Carol Rogan, DRNI, and Dr Emer Begley, NDO for the invitation to open the policy and practice forum. She welcomed the forum which she believes will help raise awareness and identify key considerations for formal service providers when engaging with the families of people with dementia, as well as highlighting how gender issues are impacting on care provision including care planning and advanced decision-making. Janette encouraged participants to enjoy the discussions and expressed her desire to receive a report on the event.

Janette closed with the following quote:

'Coming together is the beginning. Keeping together is progress. Working together is success'

She commented that this second Policy and Practice Forum is testament that organisations are working together and hopes that they will continue to work together to bring about improvements for people with dementia.

After Janette's opening address, three speakers presented findings from research on family carers. These were followed by an interview with Paddy Crosbie, a family carer and member of the LGBTQI+ community, in conversation with Dr Laura O'Philbin from the ASI.

## 4.0 The Family Care Landscape on Dementia Through a Gender Lens: Summary of presentations

### 4.1 Dr Nikki Dunne, Research Officer, Family Carers Ireland

In her presentation, **Dr Nikki Dunne** provided some context to underpin later discussions on family caring, gender and dementia care by sharing data on the extent of family caring in Ireland and findings from studies in which Family Carers Ireland (FCI) have been involved, with a specific focus on family carers of people living with dementia.

What is known about who cares in Ireland? The Irish Health Survey 2019 (CSO, 2020) showed that approximately 13% of people aged 15 years and over are providing care, which roughly equates to 500,000 family carers across Ireland. The survey shows that more females provide care than males; 14% of females provide care as compared to 11% of males. Women are more likely to take on a family caring role and Census data shows that women also tend to provide more hours of care.

Looking specifically at dementia, there are approximately 64,000 people living with dementia in Ireland. For every one person diagnosed with dementia, it is estimated that three other family members are specifically affected (Cahill, O'Shea & Pierce, 2012). It is estimated that 35,000 people with dementia are living in the community and approximately 60,000 family carers provide care to people with dementia living in the community (Pierce, Cahill and Carney, 2017). A survey providing a profile of family carers of people with dementia showed that almost three-quarters (73%) were women (Lafferty, Fealy, Teahan, McAuliffe, Phelan, O'Sullivan & O'Shea, 2016). Given the extent of family caring and the critical role that family carers play in supporting people with dementia to live at home, it is important to pay attention to family carers and have a good understanding of why and how they are affected by caring responsibilities.

Family Carers Ireland (FCI), in collaboration with the College of Psychiatrists of Ireland and UCD School of Nursing and Midwifery undertook a national survey of family carer health and wellbeing in 2018. The findings were published in a report titled *Paying the Price – The Hidden Impacts of Caring* (FCI, 2019). Family carers responding, the majority of whom were women, reported a range of impacts on their health and wellbeing. For example, just over two-thirds (67%) reported that they had been diagnosed or treated for a physical health condition. More specifically, 40% had been diagnosed with back injury and 26% diagnosed with high blood pressure. Almost half (48%) reported that they had been diagnosed or treated for a mental

health difficulty; 35% had been diagnosed with depression and 39% with anxiety. More than two-thirds (68%) reported that they quite frequently or nearly always felt that their health had suffered because of their caring role.

In the winter of 2019/2020, before the outbreak of COVID-19, FCI undertook Ireland's first national State of Caring survey, providing a snapshot of what it is like to care in Ireland. It is to be followed up every two years. The survey of the membership and network reach of FCI was distributed online and by post and completed by 1,250 family carers. Of the respondents, 142 (11%) were caring for at least one person with dementia. The majority (85%) of these respondents identified as women, and 11% as men. The average age was 52 years (SD: 10.38). Family carers of people with dementia reported that they were providing intense levels of care. Almost three-quarters (74%) reported providing over 90 hours of care per week and over half reported providing round the clock care (140 to 168 hours per week) to a person with dementia. They also reported on the length of time that they had been caring; 42% had been caring for a person with dementia for between one and four years and 30% for between five and nine years (FCI, 2020).

It is known that taking on a caring role can have long-term financial impacts such as the loss of income as a result of reducing or leaving employment to provide care and/or increased spending due to the costs associated with caring. The survey explored how family carers were coping financially with their caring role. Of the 124 family carers of people with dementia responding to the survey, 59% reported that they find it hard to make ends meet and 17% could only make ends meet with great difficulty. More than half (54%) reported that they had been in debt or would be likely be experience debt in the future. Some 40% were spending more than a total of €150 per month out of their own pocket on additional expenses associated with caring such as travel expenses, personal care products and utility bills. Consistent with findings relating to the total sample of family carers, approximately one-fifth (21%) of family carers of people with dementia who struggle financially reported that they cut back on food or heat in order to make ends meet:

“It's impossible, hospital appointments, diesel and medication that is not covered by medical card is crippling us. I cannot afford to go to my own oncology appointments. Paying [to bring] in care for a day is not possible”

The financial strain experienced by family carers was palpable in the comments made by family carers who participated in the survey and highlights the potential for family carer households to be at risk of poverty.

With respect to the impact on employment, nearly half (48%) of family carers of people living with dementia reported that they had given up work to care. Approximately one-fifth (21%) had reduced their hours of work to support the person to whom they provide care. More than one-quarter (28%) had turned down training or educational opportunities. Many could not marry their caring and working roles. More than two-thirds (69%) reported that they had lost earnings of between €15,000 and €50,000 per annum. Family carers of people with dementia also referred to the impacts of caring on career progression:

“Working full-time is stressful and tiring and affects my energy and health. I am less likely to move role or job as I could not cope with the stress on top of caring. I feel I have lessened my career opportunities as a result.”

Caring for people with dementia has long-term economic implications, which are gendered. The state pension system in Ireland uses pay-related social insurance (PRSI) contributions to assess eligibility for State Pension (Contributory). Family carers make an enormous contribution to the economy, estimated at €20bn per annum. Despite this, if a person has to give up work or take extended periods away from work because of caring responsibilities, their entitlement to a State Pension (Contributory) may be affected (FCI, 2018). Family carers who are caring over a long period of time, the majority of whom are women, are most affected:

“I gave up work to look after my children. After four years, my father-in-law got dementia and I began caring for him. He passed away and I am now caring for my mother-in-law who also has dementia and I am now a pensioner myself”.

The [Programme for Government](#) included a commitment to establishing a Commission on Pensions (Department of An Taoiseach, 2020). In its Terms of Reference, the Commission was asked to consider how the State Pension could further accommodate long-term carers. With respect to the issue of long-term caring, one of the recommendations of the Report of the Pensions Commission is that “long-term carers (defined as caring for more than 20 years) should be given access to the State Pension Contributory by having retrospective contributions paid for them by the Exchequer when approaching pension age for any gaps in their contribution history arising from caring” (The Pensions Commission, 2021, p.112). It is hoped that the recommendations of the Pensions Commission will be acted upon and help to address the difficulties faced by long-term carers when they reach pension age.

#### 4.2 Zoe Hughes, Senior Policy and Research Officer, Care Alliance Ireland

Zoe Hughes’ presentation focused on theoretical perspectives of gender and how they form our view on family caring. Historically, caring has been viewed as a ‘feminised’ activity, which means that it has been viewed and positioned as ‘women’s work’ (Hanlon, 2015). This is borne out by research evidence and, although it is not solely an Irish phenomenon, the feminised nature of caring is very evident when Ireland is examined through a historical lens. Ireland’s very gendered Constitution and its impact is one clear example of this. The impetus for the modern carers’ movement was to get women’s care work recognised (Molyneaux, Butchard, Simpson & Murray, 2011). Because of its feminisation, care work, both paid and unpaid, has been devalued. It is, for example, low paid and has a low social value, which has repercussions for how care work is supported throughout society.

Because of the feminisation and devaluation of care work, when males participate in care work, it tends to be stigmatised, and is often associated with negative connotations such as being ‘weak’ and perhaps ‘feminine’. In patriarchal societies or where a greater emphasis is placed on productivity, males can be stigmatised for doing care work as opposed to taking up more traditional roles such as being the main breadwinner. There is some evidence of young male carers experiencing a form of homophobia regardless of their sexuality (Hughes, 2018). For example, calling a male carer ‘gay’ solely because he is a family carer is a form of

homophobia. The feminisation of care has an impact on male carers and the type of supports they might need and access to these supports.

Many family carers do not identify as a 'carer', mainly because they are providing care to someone they love. They see themselves rather as a husband, a wife, a daughter, a father, a son, a grandparent, whatever the relationship might be. Relatively few men identify as a carer and as a consequence tend not to access supports. They tend to focus much more on the skills and tasks involved rather than on identifying as a carer (Ribeiro, Paul & Nogueira, 2007). This is important as self-identification as a carer has been shown to be a gateway through which carers tend to access support (Molyneaux et al., 2011). Men and women tend to favour different types of supports. Men tend to have a greater preference for side-to-side supports as opposed to face-to-face supports (West Cork Carers, 2013). An example of a side-to-side support comes from an initiative of West Cork Carers whereby a boat was chartered to give male carers an opportunity to learn about the skills and tasks involved in sailing side by side with other male carers, through which relationships were developed and peer to peer support evolved. Face-to-face supports traditionally favoured by women include attendance at coffee mornings or family carer support groups. There is evidence that these traditional gender preferences are changing. Research by Stokes (2015), for example, shows that there is resistance to perceptions of traditional masculinities when it comes to caring, i.e., male carers are resisting ideas that men should not be caring or emotional.

Traditionally, it is reported that male carers are less likely to seek supports, less likely to accept help when it is offered, more likely to feel uncomfortable at care groups, more likely to feel stigmatised and less likely to have understanding employers.

When talking about family caring and gender, it would be remiss to focus solely on the gender binary of men and women. It is important to also acknowledge trans and non-binary caring, especially because trans and non-binary communities are disrupting traditional notions of gender, including in the area of family caring. The idea that male carers need one thing and female carers need something else no longer holds true. This raises important questions such as: Can / should we continue to create binary understandings of care? Is it more useful to think about 'masculinity' & 'femininity' in care versus 'male' & 'female' in care? We can think, for example, about the commonalities and differences between the experiences of a butch woman caring and a feminine man caring and what this means in the context of dementia care.

Finally, Zoe highlighted three key recommendations from the Citizens Assembly on Gender Equality (2021)<sup>1</sup> that have relevance to family caring and the Forum's discussions:

- Delete and replace the text of Article 41.2 (woman in the home) with language that is not gender specific and obliges the State to take reasonable measures to support care within the home and wider community.
- Make special efforts to improve the visibility of men performing caring roles.

---

<sup>1</sup> <https://www.citizensassembly.ie/en/news-publications/press-releases/recommendations-of-the-citizens-assembly-on-gender-equality.html>

- Adopt a fully individualised social protection system to reflect the diversity of today's lives and to promote an equal division of paid work and care.

Led by One Family, a number of organisations including Care Alliance Ireland are working to promote the implementation of these recommendations. These recommendations are discussed in more detail in both the CAI submission to the Citizens Assembly on Gender Equality (CAI, 2020) and a document commenting on the recommendations particularly relevant to family carers (CAI, 2021).

#### 4.3 Dr Maria Pertl, Lecturer in Psychology, Royal College of Surgeons in Ireland and DRNI member

**Dr Maria Pertl** gave a presentation on findings from the DeStress study, the main aim of which was to examine the relationship between caregiver stress and cognitive functioning. While the study was not specifically focused on family caring and gender, it included many questions that are relevant to the topic. Information of relevance was collected on physical health, psychological wellbeing, service use and support for caregiving. The analysis examined differences between women and men with respect to health and wellbeing and caregiver supports. The findings raise important issues for further discussion.

DeStress is the largest study of spousal family carers of people with dementia that has been conducted in Ireland. People aged 50 years and over and co-habiting with a spouse or partner with dementia were eligible to participate. Participants were recruited in a range of ways including through media channels, community gatekeepers, local advertisements, and organisations representing and supporting people with dementia and family carers. In total, 509 family carers expressed an interest in taking part in the study. Of these, 307 were eligible to participate and 274 spousal carers consented to take part in the study. Ultimately, 252 spousal carers (68% response rate) completed the baseline survey and 205 completed the follow-up survey, representing an attrition rate of 19%.

Almost two-thirds (64.8%) of the sample were women, reflecting findings from the literature showing that the majority of family carers are women. Participants ranged in age from 50 to 90 years, with a mean age of just below 70 years (Mean: 69.64; SD: 7.84). A substantial proportion (12%) were aged 80 years and over. The participants were relatively well educated, with close to two-thirds (64.7%) educated to at least Leaving Certificate level. A minority (16.3%) were still in employment at the time of the survey. There was much variation among participants with regard to the length of time that they had been caring, ranging from one month to 19 years. On average, carers had been caring for approximately five years (SD in months: 39.29).

In relation to the overall sample, Maria highlighted three key findings from the study. First, the amount of care provided by participants was very high. On average, spousal carers provided 12 hours of care per day (SD: 6.17). Slightly over one-half (51%) provided more than 15 hours of care per day and nearly half reported that they provided round the clock care. Second, support with caregiving was reported to be low by participants. One half were the sole caregiver and a further one-fifth (20%) had one additional caregiver. Almost four in five (79%)

spousal carers provided 81-100% of the care to their spouse/partner with dementia, 42% reported receiving no assistance from family/friends in the previous 30 days, and 16% had not accessed any support services to assist them with caregiving.

Spousal carers were asked about their mental health. Their levels of depression, anxiety and burden were also assessed using the CES-D,<sup>2</sup> HADS-A,<sup>3</sup> and Zarit Burden Interview.<sup>4</sup> While the majority (79%) of spousal carers self-reported their current emotional/mental health as 'good' or 'very good', the study found that levels of depression, anxiety and caregiver burden were high. More than one in three had clinically significant levels of depression, more than one in five had significant levels of anxiety, and 45% reported moderate to severe levels of caregiver burden.

Examining the differences between women and men, the study found that male spousal carers of people with dementia had better wellbeing and greater supports than female spousal carers. These findings are in line with findings reported in the literature (Lawlor, Brennan, Robertson, Pertl, O'Sullivan, Rogers et al., 2016). With respect to supports for spousal caregiving, male carers were less likely than female carers to provide 81-100% of all care needs. Males used a greater number of support services such as respite and day care and were more likely to receive help from family and friends. Self-efficacy was higher among male carers than women. Men had greater confidence in accessing support services and greater confidence in responding to the needs of people with dementia, such as responsive behaviours. The study found consistently that men had better psychological wellbeing than women. They had lower levels of depression, anxiety, caregiver burden and stress than women and lower levels of loneliness, even though female carers reported higher levels of social connectedness. Male carers reported better sleep quality, better life satisfaction, higher quality of life and identified more positive aspects associated with providing care such as personal growth, making connections or learning new skills.

The findings raise a number of important questions about the differences between male and female spousal carers providing care to people with dementia. In her presentation, Maria reflected on three questions, offering a number of possible explanations.

The first question is: 'Why might male spousal carers of people with dementia have greater supports than female carers?' A number of possible explanations were offered. The findings could have been influenced by the recruitment strategy. The socialisation of women as carers might mean that women are less likely to ask for help and support and indeed may feel stigmatised asking for help because of societal expectations that they are natural carers and should be able to cope. This may also mean that women are less likely to be offered support due to a commonly held assumption that women are better able to manage and better able to perform caregiving tasks.

---

<sup>2</sup> Centre for Epidemiological Studies Depression Scale. Spousal carers with a score greater than 16 were assessed as having clinically significant signs of depression.

<sup>3</sup> Hospital Anxiety and Depression Scale - Anxiety. Spousal carers with a score of 11 or over were assessed as having 'probable' mood disorder.

<sup>4</sup> Zarit Burden Interview. Spousal carers with a score greater than 40 were assessed as having moderate to severe levels of caregiver burden.

The second question is: 'Why might female spousal carers of people with dementia have poorer mental health than their male counterparts?' Again, it may be that the findings are a reflection of the sample. However, it is known that in general there is a higher prevalence of depression and anxiety among women than among men. The lower prevalence among men may be linked to men's acculturation to stigma related to mental health issues, which could be a barrier to men seeking help for mental health difficulties. In addition, the study showed that female carers were providing more intense levels of care and receiving less support than male carers, which could be contributing to greater levels of burden and stress, and in turn affecting their mental health. The mental health of women carers may also be affected by reduced opportunities for social interaction as a consequence of their dementia caregiving responsibilities. In this study, women carers reported greater levels of loneliness, which could be impacting on their mental health. Another possible explanation relates to differences between men and women with respect to coping. There is some evidence to suggest that women are more likely to use emotional coping strategies. Some research suggests that different approaches to caregiving by men and women may explain gender differences in mental health outcomes. There is evidence to suggest that women may perform numerous caregiving tasks from the start, whereas men take on a fewer caregiving tasks initially and tend to work through the tasks sequentially, and this may be part of the explanation. Since confidence contributes to psychological wellbeing, differences in confidence between men and women both relating to accessing support services and responding to the needs of people with dementia may be a factor explaining differences in mental health between male and female carers. There are links between sleep quality and mental health, and the fact that a high proportion of female carers reported more disrupted sleep might be another contributing factor.

The third question is: 'What are the implications for health and social care practice?' An important point for reflection is how service providers support and interact with male and female spousal carers and to what extent does gender impact on women and men's access to care and the support that is provided. Are subconscious biases at work? The findings of the study highlight the need to provide support that is holistic and tangible and also that when supports are given that they take account of mental health issues, confidence levels of individual carers, issues related to sleep quality and to opportunities for social interaction. In addition, there needs to be recognition that male and female carers may have different needs and experiences of providing care to people with dementia.

#### 4.4 Mr. Paddy Crosbie, family carer in conversation with Dr Laura O'Philbin, The Alzheimer Society of Ireland

Paddy Crosbie was introduced by **Dr Laura O'Philbin**, who welcomed this opportunity for Paddy to speak about his experience of providing care to and his relationship with his husband Derek.

Paddy began by telling participants that he and Derek are a couple and have been together for 33 years. Derek was sadly diagnosed with early onset Alzheimer's disease when he was 59 years of age and they have been living with the condition for nine years. In the last year, Derek's dementia progressed so much that he is now living in a nursing home, where he has

settled and is very happy. While Paddy has seen many changes in Derek because of dementia, the person that Derek is remains. Paddy described Derek as 'gorgeous', a warm, generous, kind, cheeky, determined person, traits that he still displays. Derek was determined not to worry unnecessarily about his diagnosis and supported by Paddy, continued to do as much as possible, both of which contributed to the couple managing well for many years and having a wonderful life together and creating wonderful memories. Working together as a team also helped.

Laura asked Paddy about the services and supports that were available to help them live well with the diagnosis of dementia. Paddy explained that because he had been diagnosed at such a young age, there were very few services available for Derek at the time of his diagnosis, due to the lack of services for people with dementia under 65 years of age. Home help or home care, for example, was not an option at that point in time. The couple attended services such as the Alzheimer Café and some other social supports, but Derek felt that he had little in common with other people with dementia attending these group-based supports as they were a good deal older than him. Being a member of the Irish Dementia Working Group (IDWG) appealed to him, as it involved doing things such as getting involved in research, influencing change and giving something back.

Neither Paddy nor Derek had family living close by but one friend visited regularly to keep Derek company while Paddy was working. Thinking about what would have been of help to him, Paddy felt that a befriending service would have been a great resource to call upon, as it would have given him an opportunity to go out on his own, which he could rarely do. This type of support was offered by some services, but they had never been connected into them. Paddy found it hard not being able to avail of this type of support. Paddy explained the couple's reluctance to seek out such services. Their hesitancy was partly linked to being a gay couple. Caution and nervousness about inviting strangers into their home was influenced by the fact that when they first met, homosexuality was still criminalised in Ireland. There was also concern about the prospect that persons coming into the home to help may feel uncomfortable, may not be respectful or may hold prejudices against them. These issues were uppermost in their minds when seeking out and choosing services and supports. Even though homosexuality has been decriminalised in Ireland since 1993 and there have been many progressive changes, the reticence and cautiousness remained in the back of Paddy and Derek's minds. In saying that, Paddy said that neither he nor Derek has experienced any prejudice with any of the services in which they have engaged, which made a huge difference to them. This may have been influenced by the fact that Paddy was upfront with service providers letting them know that he and Derek are a gay couple and what their expectations were. Paddy publicly raised the issues facing members of the LGBT community in 2016 when he was interviewed for an article in the Irish Independent, highlighting in the media for the first time in Ireland what it was like for a gay couple living with dementia and seeking health and psychosocial services and supports. They have not met any other gay couple living with dementia.

The time came when Derek needed more support with personal care, and knowing Derek so well, Paddy insisted that the carer would have to be a male carer. However, because so few home support carers are male, the home support agency could not give a guarantee that a male care could be provided. Paddy persisted with his request for a male carer and eventually a male carer was provided. The fit between Derek and the male carer was extremely good

and they related well to each other through their shared love of rugby. Paddy feels that Derek benefited from this. In Paddy's experience, care is always seen as women's work and the feminisation of the care industry could be a challenge.

A strong belief that Paddy holds is that people providing care to Derek, including those in the nursing home setting, are working in partnership with Paddy to provide care. For example, when Derek was first admitted to the nursing home, it became immediately clear to Paddy that the staff shared his goal of keeping Derek doing as much as he can for as long as possible (as did the carers who had been providing care at home). Paddy stressed the importance of knowing that the care staff are a partner in care with the same standards and approach to care, particularly for people with dementia. Knowing this gives him great confidence and in turn his confidence and satisfaction are of benefit to Derek. A message that Paddy would like to communicate to service providers is the importance of continuity of care for people with dementia, i.e. the same person providing care. While Paddy acknowledged the challenges of doing this, he stressed that it is 'so, so important for the person living with dementia and equally for the family carer. You need to feel ok and that you can rely on this person and then the fear and stress is gone'. He believed that this feeling is the same, whether the family carer is male or female. Paddy also spoke about the challenges for family members of providing care to a person with dementia and the importance for family carers to have time to recharge their batteries and be able to continue to provide care. He gave day care as an example of a service that facilitates this and spoke very positively about his experience of day care.

Paddy finished by saying that he kept Derek at home for as long as he could and although it was a struggle to do so, it was absolutely worth it. He believes that Derek would have done exactly the same for him.

## 5.0 Panel Discussion

The panel discussion was facilitated by Dr Emer Begley, Interim General Manager, National Dementia Office, HSE. The discussion focused on starting a conversation on dementia care, family caring and the LGBTQI+ community. The panel members were:

- (1) Zoe Hughes, Senior Policy and Research Officer, Care Alliance Ireland
- (2) Dr Miriam Galvin, School of Medicine, Trinity College Dublin
- (3) Dr Lorna Roe, Research Fellow at the Centre for Health Policy and Management, Trinity College Dublin
- (4) Dr Sinéad Hynes, Lecturer in Occupational Therapy, NUI Galway
- (5) Ciarán McKinney, Engage Programme Manager, Age & Opportunity

The first question put to the panel was: **Some health and social care professionals believe that operating a sexuality blind service is needed for greater equality. What are the advantages and disadvantages of taking this approach particularly in relation to people with dementia and their family carers?**

Dr Lorna Roe's contribution to the panel discussion was informed by the issues raised at the workshop she co-led exploring the lived experience of older LGBTQI+ people in Ireland, their experience of ageing, health care and ability to age in place, and by the literature on this topic. Lorna believes that it is important to address this question from the perspective of addressing

health inequities. Health inequities are defined as differences in health that are systematic, socially produced and unfair. A systematic review on the LGBTQI+ community and ageing found that people from the LGBTQI+ community are more likely to carry a greater health burden than their heterosexual peers (Fredriksen Goldsen, Jen & Muraco, 2019). These health inequities are thought to result from a history of living with stigma, discrimination and oppression, which is associated with poorer physical health, disability, chronic disease and depression in old age. Health inequities may also be perpetuated by old age. Older people from the LGBTQI+ community reported becoming doubly invisible as they age as they can experience age discrimination from within their own youth-oriented community and age, gender and/or sexuality discrimination within society more generally. There is also evidence to suggest that people from the LGBTQI+ community may face distinct risk factors related to cognitive impairment and dementia including social isolation, discrimination, barriers to care access, limited availability of and support for family carers and higher rates of certain chronic diseases. When any of these factors driving health inequities exist, including outside of the health system, the health system plays a role in addressing health inequities and supporting healthy ageing, by addressing modifiable risk factors for diseases such as dementia and providing care and support to people living with chronic diseases.

The question is: how can health systems address the specific needs of the LGBTQI+ community? Lorna's view, which is informed by her work with older adults with complex needs, is that it is neither possible nor feasible for health systems to create a plethora of LGBTQI+-specific services. Like their heterosexual peers, many people from the LGBTQI+ community will be living with more than one health problem requiring inputs from across the health services including from general practitioners (GPs), public health nurses (PHNs), allied health professionals, hospital doctors and home care workers. Equally, the health system should not be blind to the needs of LGBTQI+ older adults. Health systems are a microcosm of society and a sexuality blind approach will reproduce existing social structures and behaviours. The workshop revealed that this is happening today in the policy and systems landscape. For example, older LGBTQI+ community groups are not able to access traditional financial supports that are available to other groups more typically defined by geographical location.

For many older LGBTQI+ people, family carers may not be available to provide care in old age. The system of care in Ireland is predominantly aimed at supplementing family caring and is not sufficient to support a person to remain living at home. Staff are not typically trained to provide culturally competent care for older people from the LGBTQI+ community. People from the LGBTQI+ community experience and are fearful of derogatory or stigmatising comments from staff and other service users. This may stop them from seeking help or engaging with services. Finally, there is limited research in Ireland on people from the LGBTQI+ community in Ireland and care, meaning that clinicians do not have the evidence on the LGBTQI+ population for designing appropriate services. Policymakers are blind to LGBTQI+ barriers to care and the costs of care for people from the LGBTQI+ community. The above serve to illustrate in a small number of ways how health services that are gender or sexuality blind negatively impact on older adults living with dementia and their carers. It is important to take a health equities perspective across the system including with respect to culture, behaviours and attitudes of staff through to policy, services and supports. The issue is not going to be addressed by a single intervention.

Ciarán McKinney suggested that we can learn from the Black Lives Matter social movement. When people were saying that ‘all lives matter’, what they were actually doing was denying the issue, which is that *black lives do matter*. Ciarán stated that:

‘If we have a sexuality blind policy, then we, and I am speaking of we as the LBGTQI+ community, could very easily be completely ignored because the societal standard is still the assumption that most people are heterosexual but, more importantly, the assumption that, as we age, we are no longer sexual. I think it is critical that we acknowledge, respect and value the fact that as older people we still retain our sexuality and that gets expressed according to our sexual orientation’.

Ciarán went on to say that within this, there is the gender identify of people who have transitioned or who are intersex. He concluded by saying that service provision can’t be blind, it has to be addressed specifically.

Zoe Hughes referred to a study from Australia showing that family carers who identified as being from the LBGTQI+ community were put off by organisations operating as sexuality blind that said that ‘we don’t discriminate, everyone is treated the same and get the same service’. Zoe acknowledged that, irrespective of sexuality, people with dementia and their family carers will experience a range of common issues (Barrett and Cramer, 2015). However, people with dementia and family carers from the LBGTQI+ community will experience additional impacts, both positive and negative, not faced by their heterosexual counterparts. It is extremely important that this is acknowledged. However, by treating everyone equally, differences between people with dementia and family carers are ignored. This has serious implications. For example, when the message is that everyone will be treated the same, people with dementia and family carers from the LBGTQI+ community may be dissuaded from raising issues or questions particular to their situation. It is also important to note that family carers may not want to ‘come out’ to the person providing care, as this can mean having to ‘come out’ over and over again and many will not want to do that.

Sinéad Hynes stated that services saying that they are operating a sexually-blind service are actually shirking responsibility. It would not be acceptable to say, for example, that our services are cognitively blind. Services are adapted to ensure that they are useful and tailored to the people who need them. If we are talking about sexuality, we are talking about partnership, activity, behaviour, attitudes and function. If all of these are neglected, a huge part of a person’s life is being neglected. Sinéad agreed with Ciarán that, as people age, and particularly for people with dementia, sexuality is often seen as irrelevant. There needs to be more focus on the issue of sexuality. Sinéad echoed Zoe’s concern about the need for people from the LBGTQI+ community to ‘come out’ over and over again. She pointed out that the onus is often on the person to educate health professionals rather than health professionals taking on responsibility for getting informed about LBGTQI+ issues in dementia care as they may do about other areas of care.

Dr Miriam Galvin added that our experience is shaped by each of our identities. By virtue of being an older person or a person with cognitive impairment, identity is almost taken away from the person because there is a sense of loss in terms of their self-perception or other people’s perception of them. For a cohort of people such as the Stonewall generation who fought as activists for recognition of their identity, there is a confluence of interest. This group

showed us how to claim a place in society and they are now reaching an age where automatically for all older people it seems to be not only is sexuality disregarded but identity as a farmer or teacher or mother is also disregarded and people with dementia instead get defined solely by their dementia. Miriam agreed that sexuality blindness potentially leads to inequities. She argued that there also needs to be recognition of intersectionality. Using the example of gender and sexuality, Miriam argued that the experience of a LGBT female is different from that of a LGBT male. Diversity needs to be acknowledged, as does the need for cultural competence, alternative decision-making, families of choice, all of which need to be accepted. In addition, as the LGBT or Stonewall group did, it may help other minority or non-normative groups to claim a place in society and for care to become more person-centred. Seeing dementia care through the lens of the LGBT community can lead to other groups of people whose needs are not being respected being also brought in. There is a great opportunity to find out what is useful for the LGBTQI+ community and ask them what they want.

Ciarán thanked Miriam for raising the question ‘what do we want?’ and suggested that what people from the LGBTQI+ community want most is acknowledgement that we exist. However, Ciarán reiterated that ‘this is not solely about being LGBTQI+, it is that, as an older person, my sexuality is still a part of me, but in many care services that part of people vanishes. It is not recognised for older people at all’. At a very basic level, that very ageist perception that older people are asexual, let alone sexual orientation or gender identify, must be challenged. Moving on from that, there needs to be an acknowledgement that: ‘I have a past. I have a history. I might have a partner or I might not. But, if I have a partner, it will be a man and he is acknowledged as my partner.’

Miriam questioned whether the absence of data on LGBTQI+ people is an indication of the invisibility of LGBTQI+ people in dementia care. This type of data is needed to be able to monitor what is happening in dementia care services.

Zoe pointed out that sexuality is about more than who a person is attracted to. It can extend to dress, for example. For a butch woman, for example, the thought of having dementia, residing in a nursing home and being dressed in very feminine clothes can be horrifying. There are reports in the literature of this kind of thing happening. Dress is part of sexuality and part of how people express themselves as a human being. There is a normative dress code and while talking about clothes may seem frivolous, it is anything but. This is an important issue for people with dementia and for understanding the whole person with dementia.

Emer agreed that maintenance of self and identity for people with dementia was hugely important, and an issue often addressed in the literature.

Sinéad highlighted the importance, in the development of dementia care services, of including people from groups of interest in any service planning, improvement or decision-making, as this will lead to better services. Efforts to identify the needs of different population groups, such as through PPI in research, is part of that.

The next question asked of the panel was: **What is it that people from the LGBTQI+ community want from health services, whether care takes place in the community, residential care setting or assisted living?**

Dr Lorna Roe said that when we think about people with dementia from the LGBTQI+ community as a category or a target population of interest, it is often assumed that all people in this group have a common identity and set of preferences. But, of course, there are many differences between people within this group. For example, they have different genders and different sexual identities, which has implications for health behaviours, health care needs, experiences and outcomes. There is limited evidence from research examining intersectionality between sexuality and ethnicity and socio-economic status, for example. While there are limits to our knowledge, what we know is that older people from the LGBTQI+ community want to feel safe and it is of great concern that they don't feel safe. Changes to staff behaviour and culture within services are required so that older people from the LGBTQI+ community do not experience discrimination and are protected and not subjected to derogatory remarks from other service users. Maintenance of identity as people age is important, which can be promoted through the use of correct pronouns, for example. The LGBT Champions programme (<https://lgbt.ie/champions-programme/>) are doing great work in this area. Miriam spoke about the inclusion of chosen family, and it is important for health professionals not to assume that the biological family takes precedence in decision-making and care provision. This assumption may lead to people having to disclose their sexual identity when they may have preferred not to. For people who wish to disclose their sexual identity, the effort of 'coming out' over and over to different staff has been referred to previously. This could potentially be overcome with the implementation of a unique health identifier record. Increasing visibility of older people from the LGBTQI+ community for policymakers and enabling their participation in research, both directing research and identifying research questions, have proved to be highly valuable. Having evidence on disparities in health would be useful, as well as examining the phenomenal strengths and resilience of this community, their social ties, strong social engagement, and what lessons there are for other communities.

Ciarán thanked Lorna for referencing the LGBT Champions programme. He chose to highlight BEING ME, an EU-funded project, which provides a substantial range of resources and best practice tools on promoting the inclusion of older LGBTQI+ persons and their family carers in residential and day care services. Ciarán recommended those with an interest in this area to visit the project's website at: <https://beingme.eu/>

On behalf of the DNRI and the NDO, Emer Begley thanked the panel members for their contributions and the speakers for their presentations on issues relating to gender, sexuality and differences in caregiving. She encouraged those working in dementia care policy, research and practice to reflect on the importance of including diverse voices and perspectives in their work. The topics discussed could help health professionals reflect on how care is provided, what personalised and individualised care can look like, as well as the ways in which individuals and their families are involved in decision-making. Finally, Emer thanked Forum attendees and brought the Forum to a close.

## 6.0 Further Information

Videos of the presentations can be found on the DRNI YouTube channel:

<https://www.youtube.com/watch?v=0RyvTAGfQIY&t=2696s>

Copies of the presentations can be found on the DRNI website:

<http://dementianetwork.ie/gender-and-dementia-care-aspects-family-caring>

## 7.0 About the Organisers

### **Dementia Research Network Ireland (DRNI)**

DRNI is an innovative, all-Ireland research initiative which supports and facilitates collaborative interdisciplinary research integrating the basic, clinical and social sciences. DRNI seeks to improve outcomes for people with dementia/ neurodegenerative disease through improving our understanding of the causes and mechanisms of neurodegeneration, the effectiveness of different models of care, and the policy changes required to improve individuals' quality of life.

The network currently comprises 121 members. Membership includes leading Irish academics, clinicians, health & social care practitioners, early-career researchers, government representatives, community & voluntary sector members, people living with dementia and Parkinson's disease, and carers. DRNI is funded by the Health Research Board (Grant No. DRNI-2021-1).

Website: [www.dementianetwork.ie](http://www.dementianetwork.ie)

Twitter: @DRNIre

Email: [info@dementianetwork.ie](mailto:info@dementianetwork.ie)

### **National Dementia Office**

The National Dementia Office (NDO) was established in 2015 in accordance with the launch of the National Dementia Strategy (Department of Health, 2014). The NDO provides leadership at a system level for the implementation of the strategy. Its role and function are to oversee the implementation, monitoring, and ongoing evaluation of the National Dementia Strategy.

The NDO sits under Services for Older People and Dementia Care, Change and Innovation within the Health Service Executive.

## 8.0 Speaker biographies

### **Dr. Emer Begley**

Dr Emer Begley is currently acting General Manager at the National Dementia Office (NDO), within HSE's Services for Older People and Dementia Care, Change and Innovation. Prior to joining the NDO in 2017 as Senior Project Manager, Emer held the position of Policy and Research Manager with the Alzheimer Society of Ireland.

### **Paddy Crosbie**

Paddy Crosbie first became involved with the Dementia Carers Campaign Network (DCCN) at its inception in 2013 due to his late partner Derek being diagnosed with early onset Alzheimer's Disease. Paddy is originally from Rosslare Harbour in Wexford and now lives in Dalkey, Dublin. He and Derek celebrated 33 years together last year, and Derek sadly passed away in November 2021. The Dementia Carers Campaign Network is supported by The Alzheimer Society of Ireland.

### **Dr Nikki Dunne**

Dr Nikki Dunne joined Family Carers Ireland in March 2019. As the organisation's Research Officer, Nikki leads Family Carers Ireland's programme of research and manages a diverse range of qualitative and quantitative projects relating to family carers. She is particularly focusing on building and coordinating research involvement and engagement among family carers, researchers and other stakeholders.

Nikki has a PhD from the University of Edinburgh, where she was based at the Centre for Families and Relationships. Prior to joining Family Carers Ireland, Nikki worked in academic research on projects relating to gender and care worker migration, archival research methods and kindness in public policy.

### **Janette Dwyer**

Janette Dwyer is the Assistant National Director for Change and Innovation, Services for Older People & Dementia Care with responsibility for Change and Innovation for Services for Older People. Janette has over 21 years of experience in healthcare service delivery within the HSE and previously held roles in the areas of national and local operational services delivery, corporate planning & performance and strategy & planning.

### **Dr Miriam Galvin**

Dr Galvin is Associate Professor of Intersectional Research Methodology in the Academic Unit of Neurology at Trinity College Dublin and leads the Health Services Research Theme. With a background in human geography, her interdisciplinary work focuses on the application of mixed methods research in clinical care, caregiver research, person reported outcomes and experiences. Her interests include socioecology, masculinities, intersectionality and discourse.

### **Zoe Hughes**

Zoe joined Care Alliance Ireland in January of 2015. Zoe has qualifications in Social Work, Social Policy and Disability Studies, and her past work has included working with a number of academic and voluntary sector organisations. She has a particular interest in the topic of

diversity within caring, along with inclusive and participatory research methods. Zoe is currently Senior Policy & Research Officer, and coordinates the Care Alliance research and policy functions. This is along with supporting member organisations to input into Care Alliance Ireland documents and submissions.

Zoe commenced work on the Doctorate in Applied Social Studies in University College Cork in October 2017, with a focus on the broad topic of family care within the LGBTQIA+ community.

### **Dr Sinead Hynes**

Dr Sinéad Hynes is an occupational therapist and lecturer in occupational therapy based at the School of Health Sciences, National University of Ireland Galway. Dr Hynes' research interest lies largely in the area of neurorehabilitation. Specifically, her research focuses on improving symptom management and quality of life for people with multiple sclerosis, and people with dementia and care partners. She is the Principal Investigator of IRC-funded research titled "*Diversifying dementia service delivery in Ireland: Developing consensus-based recommendations for the future needs of older LGBTQI+ adults*", being conducted in conjunction with Alzheimer Society of Ireland.

### **Ciarán McKinney**

Ciarán McKinney is the Engage Programme Manager with Age & Opportunity and collaborated with Dr Zoe Hughes, Dr Lorna Roe and Dr Emer Begley in the past. Ciarán participated in the discussion as a member of the LGBTQI+ community and is an activist, having been involved in gay activism since the late 1970s, a movement that has become more inclusive of trans, bisexual, lesbian and intersex people.

### **Dr Laura O'Philbin**

Dr Laura O'Philbin is the interim Research & Policy Manager at The Alzheimer Society of Ireland. Laura has a PhD from the Dementia Services Development Centre in Wales and a background in Psychology. She previously worked in academic research before moving to The Alzheimer Society of Ireland in 2019.

### **Dr Maria Pertl**

Dr Maria Pertl is a lecturer in the Department of Health Psychology, RCSI University of Medicine and Health Sciences in Ireland. Her research interests include interrelationships between chronic stress, health-behaviours, and health and wellbeing. She led De-Stress, a large longitudinal study, funded by the Alzheimer Society of Ireland and the Health Research Board (Principal Investigator Prof Brian Lawlor), that examined relationships between cognitive function, physical and psychological health outcomes and the stress associated with caring for a spouse with dementia. This project provided key insights into the level of care that spousal dementia caregivers provide in Ireland, the extent of supports available to them and how these relate to caregiver wellbeing.

### **Dr Lorna Roe**

Dr Lorna Roe is a Research Assistant Professor at the Centre for Health Policy and Management in Trinity College Dublin and a member of the health economics and policy research staff at The Irish Longitudinal Study on Ageing (TILDA). She also holds positions

as a Senior Atlantic Fellow for Equity in Brain Health at the Global Brain Health Institute (GBHI), is an elected member of the Board of Trinity College Dublin, an invited board member of the Institute of Obstetrics and Gynaecology in Ireland, and a member of the Committee of the Irish Social Policy Association.

Lorna's work focuses primarily on examining how systems and policies can better support older adults living with complex health needs, where the evidence shows care experiences and outcomes are often poor, while costs are high. She is also interested in exploring the intersectionality of social identities on the experience of ageing and on care experiences and outcomes. Lorna is currently the Principal Investigator of the FRAIL-COG study, a Health Research Board funded study which examines the impact of frailty and cognitive decline on patterns and costs of care.

**Dr Carol Rogan**

Carol Rogan is Scientific Project Manager for Dementia Research Network Ireland (DRNI). Carol supports and facilitates collaborative interdisciplinary research integrating the basic, clinical and social sciences. Through outreach activities, policy & practitioner fora and tailored information & communication strategies, Carol supports the network to build on existing research and to positively influence dementia research and policy making. Prior to her role in DRNI, Carol worked in the disability sector and conducted research in the area of Acquired Brain Injury.

## References

- AARP and National Alliance for Caregiving (2015) *Caregiving in the US 2015 Report*, NAC and AARP Public Policy Institute, <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
- Bamford, S.M. (2011) *Women and Dementia: Not Forgotten*, London: International Longevity Centre.
- Barrett, C. and Cramer, P. (2015) *An Extra Degree of Difficulty: An Evidence Based Resource Exploring the Experiences and Needs of Older LGBTI Carers and the Carers of Older LGBTI People*, Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University.
- Bartlett, R., Gjernes, T., Lotheringon, A-T., Obstfelder, A. (2018) Gender, citizenship and dementia care, *Health and Social Care in the Community*, 26(1), 14-26.
- Cahill, S., O'Shea, E. and Pierce, M. (2012) *Creating Excellence in Dementia Care: A Research Review to inform Ireland's National Dementia Strategy*, Dublin and Galway: Trinity College Dublin and National University of Ireland Galway.
- Care Alliance Ireland (2020) *Submission to the Citizens Assembly on Gender Equality*, Dublin: Care Alliance Ireland, [https://www.carealliance.ie/userfiles/files/CAI\\_Citizens\\_Assembly\\_Consultation\\_Submission\\_2020.pdf](https://www.carealliance.ie/userfiles/files/CAI_Citizens_Assembly_Consultation_Submission_2020.pdf)
- Care Alliance Ireland (2021) *Recommendations from the Citizens Assembly on Gender Equality: Focus on those recommendations particularly relevant to family carers*, Dublin: Care Alliance Ireland, [https://www.carealliance.ie/userfiles/files/Citizens\\_Assembly\\_Care\\_Rec\\_CAIComment.pdf](https://www.carealliance.ie/userfiles/files/Citizens_Assembly_Care_Rec_CAIComment.pdf)
- CSO (2020) *Irish Health Survey 2019*, <https://www.cso.ie/en/releasesandpublications/ep/p-ihsc/irishhealthsurvey2019-carersandsocialsupports/>
- Department of An Taoiseach (2020) *Programme for Government: Our Shared Future*, <https://www.gov.ie/en/publication/7e05d-programme-for-government-our-shared-future/>
- Department of Health (2014) *The Irish National Dementia Strategy*, Dublin: Department of Health.
- Family Carers Ireland (2018) *Carers and the State Pension: A Guide to the Pension System for Family Carers*, Dublin: Family Carers Ireland.
- Family Carers Ireland, the Irish College of Psychiatrists and UCD School of Nursing, Midwifery and Health Systems (2019) *Paying the Price – The Hidden Impacts of Caring*, Dublin: Family Carers Ireland, <https://familycarers.ie/media/1422/paying-the-price-the-hidden-impacts-of-caring.pdf>
- Family Carers Ireland (2020) *The State of Caring 2020*, Dublin: Family Carers Ireland, <https://familycarers.ie/media/2022/family-carers-ireland-state-of-caring-2020.pdf>
- Fraser, N. (2000) Rethinking recognition, *New Left Review*, 3, 107-120.
- Fredriksen Goldsen, K.I., Jen, S., Muraco, A. (2019). Iridescent Life Course: LGBTQ Aging Research and Blueprint for the Future - A Systematic Review. *Gerontology*, 65(3), 253-274. doi: 10.1159/000493559.
- Greenwood, N. and Smith, R. (2015) Barriers and facilitators for male carers in accessing formal and informal support: A systematic review, *Maturitas*, 82, 162-169.

- Greenwood, N. and Smith, R. (2019) Motivations for being informal carers of people living with dementia: a systematic review of qualitative literature, *BMC Geriatrics*, 19, 169.
- Hanlon, N. (2009) 'Masculine identities and affective equality: Exploring love and care in men's lives' in Cervantes-Carson, A. and Oria, B. (Eds.) *Intimate Explorations: Reading Across Disciplines*, Oxford: Interdisciplinary Press, pp. 761-783.
- Hanlon, N. (2015) 'Masculinities, Caregiving and Equality', Conference presentation to 20 Years of Family Carer Research in Ireland, Dublin, 21 November 2015.  
<https://carealliance.ie/userfiles/file/Masculinities%20&%20Care%20in%20Personal%20Life;%20Hanlon.pdf>
- Holmes, O. (2020) 'Sexuality Blindness: A New Frontier of Diversity Resistance' in Thomas, K.M. (Ed.) *Diversity Resistance in Organisations*, 2<sup>nd</sup> Edition, Oxon: Routledge.
- Hughes, Z. (2018) *Family Caring and Minority Populations*, Dublin: Care Alliance Ireland,  
[https://www.carealliance.ie/userfiles/file/Family\\_Caring\\_Minority\\_Populations\\_CAI\\_2018.pdf](https://www.carealliance.ie/userfiles/file/Family_Caring_Minority_Populations_CAI_2018.pdf)
- Lafferty, A., Fealy, G., Teahan, A., McAuliffe, E., Phelan, A., O'Sullivan, L. and O'Shea, D. (2016) 153 Profiling family carers of people with dementia: Results from a national survey, *Age and Aging*, 45(2), ii13-ii56. <https://doi.org/10.1093/ageing/afw159.151>
- Lawlor, B., Brennan, S., Robertson, I., Pertl, M., O'Sullivan, M., Rogers, J., Galvin, A. and O'Donnell, K. (2016) *Stress and Cognitive Functioning among Spousal Dementia Caregivers in Ireland: A Report of Key Findings from the De-Stress Study*, Unpublished.
- Molyneaux, V., Butchard, S., Simpson, J. & Murray, C. (2011) 'Reconsidering the term 'carer': A critique of the universal adoption of the term 'carer', *Ageing and Society*, 31(3): 422-437.
- Pierce, M., Cahill, S. and Carney, P. (2017) 'Informal Caregiving to People with Dementia' in O'Shea, E., Cahill, S. and Pierce, M. (Eds.) *Developing and Implementing Dementia Policy in Ireland*, Galway, National University of Ireland, Galway, pp. 39-47
- Ribeiro, O., Paul, C. and Nogueira, C. (2007) 'Real men, real husbands: Caregiving and masculinities in later life, *Journal of Aging Studies*, 21(4): 302-312.
- Robinson, C.A., Bottorff, J.L., Pesut, B., Oliffe, J.L. and Tomlinson, J. (2014). The male face of caregiving: A scoping review of men caring for a person with dementia, *American Journal of Men's Health*, 8(5), 409-426.
- Stokes, A. (2015) *A Never-ending Love Story: A Narrative Exploration into the Experiences of Men who Provide Care in the Context of Dementia*, Unpublished PhD Thesis, Dublin: University of Dublin, Trinity College Dublin.
- The Pensions Commission (2021) *Report of the Commission on Pensions*, The Pensions Commission [file:///C:/Users/New/Downloads/200480\\_564ea175-28b2-417d-aa9b-3f1750225310.pdf](file:///C:/Users/New/Downloads/200480_564ea175-28b2-417d-aa9b-3f1750225310.pdf)
- West Cork Carers (2013) 'Males Carers: Ireland's Unsung Heroes', *Irish Examiner*, 29 August 2013.
- World Health Organization (2012). *Dementia: A Public Health Priority*. Geneva: World Health Organization.
- Zappone, K. (2003) *Re-thinking Identity: The Challenge of Diversity*, Joint Equality and Human Rights Forum.  
[https://www.ihrec.ie/app/uploads/download/pdf/rethinking\\_identity\\_the\\_challenge\\_of\\_diversity.pdf](https://www.ihrec.ie/app/uploads/download/pdf/rethinking_identity_the_challenge_of_diversity.pdf)

## Abbreviations

ASI	Alzheimer Society of Ireland
CAI	Care Alliance Ireland
CES-D	Centre for Epidemiological Studies-Depression Scale
CSO	Central Statistics Office
DCCN	Dementia Carers Campaign Network
DRNI	Dementia Research Network of Ireland
EU	European Union
FCI	Family Carers Ireland
GBHI	Global Brain Health Institute
GP	General Practitioners
HADS-A	Hospital Anxiety and Depression Scale-Anxiety
HSE	Health Service Executive
IDWG	Irish Dementia Working Group
LGBTQI	Lesbian, Gay, Bisexual, Transexual, Queer and Intersex
MTRRs	Memory Technology Resources Rooms
NDO	National Dementia Office
NUIG	National University of Ireland, Galway
PHN	Public Health Nurse
PPI	Public and Patient Involvement
PRSI	Pay-related Social Insurance
RCSI	Royal College of Surgeons in Ireland
SD	Standard Deviation
TCD	Trinity College Dublin

TILDA      The Irish Longitudinal Study on Ageing

UCD        University College Dublin

WHO        World Health Organization