

## **From Rural Citizenship to the Rural Citizen:**

### **Farming, Dementia and Networks of Care**

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Accepted for Journal of Rural Studies 9<sup>th</sup> Sept 2018

### **1. Introduction**

Citizenship is gaining increased attention in the social sciences but has been under-utilised in rural studies. It refers to a person's relationship with a political unit (Cheshire and Woods, 2009) but has also been used to understand how meanings of belonging and identity shape the ways that individuals participate in society (Bullen and Whitehead, 2005; Desforges et al., 2005; Painter and Philo, 1995; Stevenson, 2001; Yarwood 2014). Anderson et al. (2008, 34) contend that:

*Citizenship is increasingly organized and contested through a variety of non-state as well as state institutions. This extends citizenship in the cultural sphere,*

*to describe people's senses of belonging in relation to places and people, near and far; senses of responsibility for the ways in which these relations are shaped; and a sense of how individual and collective act.*

As Smith (2000) notes, the idea of citizenship straddles social, cultural and political practices and, consequently, provides a way of linking concerns about individual identity and performance with knowledge about how these are shaped, and shape, broader political structures. Although some scholars have started to explore how citizenship is manifest in the countryside (Parker, 2006; Woods, 2006; Yarwood, 2017), these have tended to focus on the more political aspects of citizenship at the expense of its significance in daily life.

This paper attempts to widen understandings of rural citizenship by exploring the impact of dementia on the lives of farmers and their families. Citizenship is helpful because it not only draws attention to the ways that farmers interact with formal and informal networks of care, but also the extent to which they are able to participate as full members of society. These issues are examined in different rural spaces that range from the farmhouse, to local social networks and through to wider legal-economic networks of business. In doing so, the work also aims to shed light on the lives of people living with dementia in rural places in order to inform emerging policies and practices of care (Innes et al., 2011). The paper begins by assessing work on rural citizenship before applying this to a study of dementia in rural Devon.

## **2. From Rural Citizenship to Rural Citizen**

Ideas of citizenship are fluid and, like rurality, there is no universal definition of the term. To date, work in rural studies has tended to use the well-established idea that citizenship is the relationship between a person and a political body, usually the nation-state (Mitchell, 2009). This is usually manifest in terms of the rights a citizen is entitled to from the state and the duties that he or she is expected to undertake in return. Various studies have used the language of rights and duties to consider the relationship of rural citizens with the state and, at the same time, examine the ways in which political interventions, be they from the state or citizen, influence how these are played out in various rural places and scales. Tonts and Larsen (2002,135), for example, use the language of human rights to draw attention to differences in service provision in rural places arguing that ‘as governments withdraw, or fail to provide, certain services and infrastructure the human rights of rural people are diminished.’ Cresswell (2009) goes so far as to suggest that services and transport are so important to citizens that they may be viewed as ‘prosthetics’ that are necessary to enable full participation in society. In rural places, isolation, poor transport links and lack of services combine to render many people immobile, partial-citizens who are unable to access the rights afforded to other sectors of society. The rhetoric of rights has also been deployed by rural pressure groups seeking to recognise and address these inequalities (Woods, 2003). In some cases concerns about rural rights have led to insurgent forms of citizenship, such as the Landless Rural Workers Movement (Wittman, 2009) that have adopted autonomous forms of action to effect change, often at a transnational scale (Yarwood, 2017). Other campaigns attempt to link ethical (urban) consumers in the Global North with producers in the (rural) Global South and have been attributed to developing a heightened sense of ‘global citizenship’ (Clarke et al., 2007; Evans, 2011).

It is also possible to identify a strand of literature that has examined the duties of rural citizens, largely through policies that have encouraged various forms of 'active citizenship'. Rural citizens have been increasingly required to fill gaps left behind from the neo-liberal roll-back of the state by, for example, volunteering to run services hitherto provided by the state including housing, policing and health services (Barnett and Barnett, 2003; Farmer et al., 2012; Jones and Heley, 2016; Yarwood and Edwards, 1995). The result is a patchwork of services that reflects willingness or capacity to engage with active citizenship policies (Desforges *et al.* 2005).

While this work is valuable, it has tended to emphasise political or policy aspects of citizen participation. Mackian (1995) argued that, for many, citizenship has little to do with politics and is more about living out daily lives as ordinary people. Drawing on the example of health care, she suggested that most people are unwilling to involve themselves in new opportunities for the citizen governance of health but, rather, are simply engaged with keeping well or getting better from illness so that they can engage in daily life. She concludes a patient's 'own active citizenship is something which blends imperceptibly into the life of the community' (Mackian, 1998: 35) rather than the spatial and social politics of health care. Staeheli (2011, p.399) also argues that

*Daily repetitions that are part and parcel of the relationships that construct and disrupt citizenship – are important to the lives of people and to the potential of citizens to act.*

Painter and Philo (1995) also urged scholars to embrace more 'human' conceptualisations of citizenship, especially those that engage with the social and

cultural practices of inclusion and exclusion in the spaces of daily life. This has led to a closer focus on the spaces of citizenship that exist below, between and within the nation-state (Cresswell, 2009; Desforges et al., 2005). Bullen and Whitehead (2005: p.499) consider that this has led to 'a changing spatial focus concerning where citizens are to be found—from the town hall to the ghetto; the public square to the private home; the city to the edge community'. Indeed, it has been recognised that rural space can be significant to the perpetuation of particular visions of citizenship. Youth Hostels, national parks and the countryside have also provided settings for expeditions, nature rambles and crafts aimed at teaching young people the values of citizenship (Lorimer, 1997; Matless, 1996; Mills, 2016; Yarwood, 2017).

All of these examples, though, treat rural space as unusual and challenging. There is still much scope to explore other ways in which citizenship and rurality are co-constructed, especially in everyday situations. In doing so, it is important to recognise that citizenship takes place simultaneously at multiple and overlapping scales (Closs Stephens and Squire, 2012b; Desforges et al., 2005; Dobson, 2003; Painter, 2002). In a rural context, a farmer may engage with local farming communities (for example, young farmers clubs, the local livestock market, the NFU), the state (DEFRA, EA) as well as international policy frameworks (CAP) at the same time.

One way of recognising this flat ontology of scale (Jones et al., 2007) is to pay more attention to the citizen her/him-self. Rather than considering how citizenship is manifest at different scales, it is perhaps more helpful to consider how the individual citizen engages with different social, cultural and political networks at a range of scales. Staeheli (2011: 400) argues that it is 'useful to think about how people negotiate the many citizenships that frame their lives and that they, through their practices and acts, help to construct.' She goes on to argue that in the clamour to study citizenship, the

experiences of the individual citizen are often neglected and, like the cartoon figure of Waldo/Wally, is often lost in efforts to paint the big picture of citizenship. There needs to be a move away from rural *citizenship* towards the rural *citizen*. A closer focus on the individual draws attention to the different ways that a person engages as a citizen with different networks and scales, often simultaneously.

To begin this undertaking, we examine farmers living with dementia. We chart the complex terrain of rural citizenship from their rights as patients, the duties that others are required to undertake and, more generally, how farmer citizens with dementia daily engage with wider society. In doing so, we consider how both the illness and the rural context shape the ability of farmer citizens to engage as rural citizens.

### **3. Dementia and the Farmer Citizen**

We focus on dementia in the countryside for three reasons. First, dementia is increasingly significant to the daily lives of rural people (Bould et al., 2018). The illness mainly affects those over 65 and, given increasingly elderly populations in the countryside and the already high incidence of dementia in rural places, looks set to increase further (Alzheimer's Disease International, 2016; Bould et al., 2018; Burholt and Dobbs, 2012; Dowrick and Southern, 2014).

Secondly, frameworks of citizenship contribute to understandings of the illness and how it affects people's ability to participate in society. It has been suggested that those who are ill or disabled are often excluded from full participation in society due to the social organisation of space (Hastings and Thomas, 2005; Kitchin, 1998). Poor urban design, immobility and behaviour, such as staring or commenting, have contributed to exclusionary practices that have rendered people living with mental and

physical illnesses as ‘shadow citizens’ with rights in principle but not in practice (Chouinard, 2001). In rural areas, these issues are often exacerbated due to increased visibility, a lack of privacy and perceptions of stoic, close knit, supportive, homogenous communities (Parr et al., 2004; Malatzky and Bourke, 2016). Kontos et al. (2017, p.184) argue there is a need for ‘relational citizenship’ in the provision of care to those with dementia. This should incorporate ‘an individual’s relations with others into the socio-political landscape’ (p.184) and, more significantly, recognise the agency of the individual and the importance of ‘interdependence, reciprocity, and the support of persons with dementia as active partners in their own care’ (p.182-183).

It is important, then, to recognise dementia as embodied, relational and socially constructed (Philo et al., 2003; Pini et al., 2017). As Parr and Butler (1999: 4) remind us, ‘at present society plays the dominant role in constructing disability, but the role of physical and mental impairments cannot be ignored’. Dementia may have little direct impact in its early stages but, as it progresses, there is a greater need for care and medical support (Blackstock et al., 2006; Heron and Rosenberg 2017). Both the illness itself and the nature of care affect a citizen’s ability to participate in not only society, but also daily life itself.

Dementia is an umbrella term for ‘a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language’ (Alzheimer’s Society, 2018, no pagination). It can be caused by illness<sup>1</sup> or strokes<sup>2</sup> and, while some medical treatments can slow its progress, dementia is irreversible. Symptoms are initially mild but they are progressive and impair a person’s ability to participate fully in society. Some people with dementia have difficulty communicating and may repeat themselves,

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<sup>1</sup> Alzheimer's disease, for example, is caused by the build-up of proteins in the brain that cause a loss of connection between nerve cells, followed by the loss of brain cells and tissue.

<sup>2</sup> In vascular forms of dementia damaged or diseased blood vessels reduce the blood supply to the brain with corresponding loss of function.

fail to comprehend some words or struggle to follow a conversation. There may also be a loss of visuospatial skills including the ability to judge distance or see objects in three dimensions, rendering tasks such as navigating stairs or parking a car more difficult (Alzheimer's Society 2018). Some may also find it difficult to concentrate or plan, making it challenging to solve problems, come to decisions or carry out sequential tasks such as cooking meals. Others may also become disorientated, confused or lose track of time. Those living with dementia may also suffer from depression and anxiety, especially in the early stages, when they are aware that they are experiencing some of its symptoms. The corporeal symptoms of dementia therefore make it difficult for citizens to participate in daily life in the ways that they would like to but the way the illness is perceived and engaged with by wider society also has important implications for citizenship.

Thirdly, therefore, the various ways that this care is provided draws attention to the rights and duties associated with living with dementia. In England, these are outlined in the 'Prime Minister's Challenge on Dementia 2020' (PMCD). This outlines the standards that a patient has the right to expect, including the identification and assessment of dementia. One target, for example, has been to assess patients for dementia within six weeks of referral and maintain a 67% national dementia diagnosis rate, although there is recognition that spatial variation in provision exists, such as rural areas, and different social groups of people, including ethnic minorities. At the same time, there is also a greater emphasis on care *by* the community. One prominent initiative has been led by Alzheimer's Society to provide training to individuals to become 'Dementia Friends' (Bould et al., 2018). This involves educating people to recognise the signs of dementia and how to respond to people with the illness. Emphasis has been placed on teaching people in public positions, for example



shopkeepers or bus drivers, about dementia in order to enable people with the condition to go about their daily lives in a safe and inclusive way. This idea is being extended to communities, which are encouraged to apply for 'dementia-friendly status' on the basis of seven criteria that aim to raise awareness, put in place structures to support locally-identified needs and monitor progress (Bould et al., 2018).

Whilst levels of individual support depend on the severity of the condition, there is, nevertheless, considerable variation in and between countries. Rates of diagnosis vary and, once diagnosed, there is sometimes a lack of clarity as to who is responsible for providing support (Dal Bello-Haasm et al., 2014; Herron et al., 2016; Innes et al., 2005; Kumpers et al., 2006; Morgan et al., 2015). It is also important to understand that aspects of dementia are socially constructed and the organisation of society, rather than a person's symptoms, is often the main cause of exclusion, particularly in the early stages of the illness (Clarke and Bailey, 2016). Blackstock et al. (2006) found that many families with dementia felt that they were better off living in a rural area because the levels of care were higher. In part, this sprang from a 'myth' that associated rurality with resilience and self-sufficient communities that were better able to cope with dementia (see also Malatzky and Bourke, 2016). Yet they also conclude that rural people were realists that were skilfully able to identify and negotiate the disadvantages associated with care in the countryside. Building on this work, Innes et al (2006) suggest that a reflexive conceptualisation of rurality can lead to better service provision that recognises and responds to individual experiences of rurality.

The key here is in understanding how people with dementia negotiate rurality in their daily 'life-worlds', which Philo et al. (2003, p.263) refer to as 'the everyday lives of people with both incipient and diagnosed mental health problems as they struggle to cope with the everyday hassle of living, maybe working and possibly 'playing'

(spending leisure time) in rural areas.’ This is reflected Bartlett et al.’s (2010, p.37) conceptualisation of social citizenship as

*a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level.*

Social citizenship, then, draws attention to, and offers us the chance to examine, how dementia affects people’s status, identity and participation in everyday society. Some researchers refer to this as ‘narrative citizenship’ (Baldwin 2008) or the way that ‘people with dementia position themselves in relation to others, and in so doing have to negotiate their own and other’s understandings of dementia.’ (Clarke and Bailey, 2016, p.434). This not only includes how illness affects their body but also their relationship with different people and agencies that shape the daily ‘life-worlds’. The multiple meanings and scales of citizenship offers a way of charting this complex terrain and examining how those with dementia live their lives in relation to wider society.

#### **4. Methodology**

We draw upon a study of farmers and farming families living with dementia in Devon, a predominantly rural county in the UK. In 2012, 13,312 people were estimated to have dementia in Devon (1% of the population) and this figure is predicted to nearly

double by 2030 as population ages (Public Health Devon and Devon County Council, 2014). Our focus on farming is not to somehow privilege farmers or to suggest that farmers are in greater need than other members of the population in rural places (Pini et al., 2017). Rather, the multiple and overlapping sites of farming, that range from global trade networks to the space of the farmhouse, allow insights into the ways that citizenship, and the farmer citizen, entangles with public and private spaces.

Interviews were conducted with farming households in Devon (Table 1). Our interviewees included people living with the early stages of dementia, which posed ethical and methodological challenges. Before starting the research, we both undertook training offered by the Alzheimer's Society to become 'Dementia Friends'<sup>3</sup>. Particular emphasis was placed on listening to people and offering them encouragement to speak. Bearing this in mind, we designed a semi-structured interview framework that gave opportunities to ask about life experiences but, above all, offered opportunities to listen to the interviewee.

A systematic snowballing method was used to identify farmers willing to be interviewed. This approach relied on media coverage, attending agricultural events (such as markets and shows) and liaison with key contacts. It resulted in interviews with ten farming families. In order to gain a broader perspective on the challenges of providing support to this sector, a further six interviews were conducted with stakeholders from different professional and organisational perspectives working with, and supporting, farmers living with dementia and their families (see Table 1 below).

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<sup>3</sup> And in doing so became enrolled as active citizens into networks of dementia care, illustrating that citizenship is a 'complex creature' (Woods, 2006) that is both an object of enquiry and form of engagement.

Interviews lasted between 30 minutes and 1 hour, 50 minutes and were conducted at the interviewee's choice of location, usually on their farms. All were audio recorded and transcribed verbatim for analysis.

Table 1: Summary of Interviewees

<b>Interviewee Context</b>	<b>Interviewee(s)</b>	<b>Farm location/area covered</b>	<b>Context</b>
Upland farm support and development organisation	Upland Network Project Manager (female)	Uplands in Devon	Organisation was set up to ensure a viable future for upland farmers. Organisation supports farmers to establish and run projects to add value to their businesses and to increase skills.
Farming family 1	Male farmer (cattle breeding) and his mother (dementia)	North Devon	Mother was diagnosed with dementia in 2012. Currently living on the farm in a self-contained annexe. Interviewee has Power of Attorney and organises her daily care
Farming family 2	Female farmer and her daughter (dairy and beef cattle, and mixed activities)	Mid Devon	Father (recently died) a tenant farmer, suffered from dementia for more than 15 years. Father and mother continued living on the farm. Daughter and son-in-law managed the farm on their behalf (although they lived several miles away). In 2012 father's condition deteriorated further and farm tenancy was surrendered. Father (the named tenant) moved to a care home.
Rural community dementia support organisation	Project Manager (female)	South Devon	Organisation works as a Parish-based signposting service to support those living with dementia and their families. Organisation also runs regular weekly classes and organises activities and events specifically tailored to those living with dementia in the rural area
National farmer to farmer support organisation	Volunteer (male)	Interviewee has Devon-wide remit	Charitable organisation works to support farmers and their families during difficult times. Acts as a networking and support organisation and signposts to key services. Interviewee is a volunteer in the organisation
Local Authority dementia support initiative	Dementia Support Project Manager (female)	Interviewee has Devon-wide remit	Project run by local authority to signpost to relevant health and social care services for those living with dementia. Focus on rural communities
Legal practice	Agricultural Partner (male); Legal Director (female)	Interviewees have Devon-wide or national remits	Legal Director is appointed by the Court of Protection as Deputy for property and financial affairs for clients who do not have capacity to manage their own affairs. Agricultural Partner is head of the agriculture and rural business team

			and primarily focuses on supporting clients in agriculture or with rural or specialist land holdings. Interviewee also has past personal experience of supporting a parent living with dementia on the farm
Focus group – members of rural farm support organisation	Five female rural upland farmers (sheep and mixed activities) and one retired rural police officer (male)	Dartmoor-wide	Five participants actively farming. All had experience of dementia in a close relative. Retired Police Officer also experienced in incidents involving those living with dementia in rural communities in Devon
Farming family 3	Male Farmer (Mixed farm with sheep)	West Devon	Father had dementia. Interviewee arranged daily care and then care home. Father subsequently died. Mother has mental health issues and was not able to help with father's care
Farming family 4	Male Farmer (mixed farm with sheep)	South Devon	Mother has dementia, both parents elderly and infirm. Interviewee is their main carer and runs the farm. Interviewee also oversees neighbouring farm for another family member with dementia
Farming family 5	Retired male farmer (arable)	Mid-Devon	Interviewee's wife has vascular dementia. Interviewee was her main carer until she went into a care home.
Farming family 6	Daughter of farmers (works outside of agriculture)	West Devon	Father has dementia and farms 15 miles away. Interviewee supports farming activities (practically and financially) to enable father to continue living on the farm
Farming family 7	Female farmer (cattle)	Mid-Devon	Husband has dementia and is currently in a care home. Interviewee struggling to pay care home fees and remain on the farm. Son manages the stock and land (rented out)
Farming family 8	Male farmer and his son (mixed farm)	Mid-Devon	Farmer (father) may have dementia (not diagnosed). Sons now run the farm, day-to-day and family all share caring responsibilities.
Farming family 9	Daughter of farmers. (works as a case worker for farming charity)	South Devon	Interviewee's mother had dementia. Her father retired from the farm and cared for her mother. Her brother took over running the farm but he also had health issues.
Farming family 10	Male farmer (of sheep) and his mother (with dementia)	South Devon	Mother has dementia and lives in a separate bungalow on the farm. Interviewee organises her day to day care

Data were analysed using a thematic approach, where a set of themes was devised and used to guide node formation during the NVivo coding process. The following sections present the results of this fieldwork and are structured around themes of citizenship. First, the rights of citizens to access services are considered

and, following this, attention is given to forms of active citizenship in caring for those with dementia. The final section considers social citizenship and how those with dementia are able to participate in daily life. Throughout, attention is given to the individual farmer citizen.

## **5. Rights: access to services**

Medical and welfare support for dementia in Devon is provided through a multi-agency partnership that draws upon the private, state and voluntary sectors. Devon's Dementia Strategy aims to raise public awareness of the illness, improve early diagnosis and support people living with dementia (Public Health Devon and Devon County Council, 2014). The responsibility for diagnosis largely rests on the state and its National Health Service. Here the emphasis has been on improving rates of diagnosis through GP education and raising awareness of the illness in support agencies. In 2013, Devon had a diagnosis rate of 41.9% compared to a national average of 48% and a national target of 67%. While it is difficult to ascertain a spatial pattern, some rural districts had lower rates of diagnosis. In 2017 the largely rural area of 'Moor to Sea' in South Devon had rates of only 46.6% diagnosis compared to more urban 'coastal areas' (65%) or the town of Newton Abbot (72%) (Joint Strategic Needs Assessments for South Devon and Torbay, 2017).

Provision for people in the later stages of dementia is often delivered by care homes, which are paid for by public and private finances. This diverse landscape of care, while commendable for its intent and range, is nevertheless complex, so much so that one charity has published a 'Dementia Roadmap' to chart services for people with dementia (Dementia Roadmap 2018). As yet, though, little is known about how individuals engage in this landscape.

Our work suggests that there were barriers that prevented farmers engaging with these agencies. Thus, many interviewees felt disadvantaged by living in a rural location and working on a farm. This was not only in physical terms, although issues such as bad weather, poor roads and distance were identified, but it was also felt that agencies were urban-centric and unable to fit with farming working patterns. Thus, one farmer stated:

*I'd been working on them since last October to give me a lunchtime visit ... they're sending someone out from Barnstaple to cook a microwave meal and take her to the toilet every day now. They only wanted to do it for quarter of an hour; we've said that wasn't long enough. Well we finally, after fighting them since last October, we got it sorted out this morning [five months later]* Farming family 1: Male Farmer.

These comments in part confirm Tonts and Larsen's (2002) view that people living in the countryside face disadvantage when trying to access services and, as such, their rights as citizens are diminished in comparison with urban residents. Yet, while isolation and farming working practices were significant, it seems that the biggest barrier to engaging services were farmers themselves, especially men. Many families recalled that farmers in early stages of dementia refused to seek help or a diagnosis:

*They don't want to know about dementia. They get a diagnosis of dementia, it's really scary, they don't know what to do about it, so they just stick their head in the sand, so fear is a massive barrier for getting help ... and feeling like you don't want to ask for help, you oughtn't to, and feeling like you ought to be able to cope*

*with it, and everybody else must be coping ... if you highlight it then you're admitting there's a problem, some people are very proud, so it's pride.* Rural community dementia support organisation Project Manager

This was attributed to a perception that farmers should be resilient and self-sufficient (Blackstock et al., 2006). Thus, one woman recalled how she had tried to seek help for her father:

*The biggest argument we ever had was when I said to Dad, I've arranged for some carers to come in and he was absolutely furious with me, because he thought he could manage and I could see that he wasn't managing ... I said, "Right, we'll cancel it"; "No, no, you've arranged it," he said, "you've arranged it we'll do it." And, actually, it was the best thing that ever happened, because it was very good carers from then on in.* Farming family 9: Daughter of farmer.

*The farming community would be reluctant to want to go to the doctor unless it's really, really, critically essential. I'm not the sort of person that would make a fuss: the trials of healthcare, no!* Farming Family 8: Male farmer.

These examples emphasise that citizenship is something social rather than political (MacKian, 1995). Farmers wanted to engage in society by carrying on with their farming lives with the 'minimum of fuss' rather than claiming rights as patients or engaging with civil society. The reluctance to seek medical help or engage with the health system may contribute to lower diagnosis rates in rural areas Joint Strategic Needs Assessments for South Devon and Torbay, 2017.



There were cases in which the private space of the farmhouse could be employed to encourage farmers and their families to use medical or welfare support. In one instance, a family member recounted how the space of the farmhouse was used to ask a farmer to accept treatment:

*Doctor [X] was absolutely wonderful. He did come to the farm and he had such a nice manner putting dad at ease. We just sat round the kitchen table and ... that helped an awful lot. And that triggered dad going onto the first medication.*

Farming family 2: Wife and daughter.

The farm is also a semi-public business space that is regularly visited by outside agencies, such as vets or tanker drivers, who became alerted to the illness. One third-sector support worker recounted occasions that vets had drawn his attention to a farmer with dementia:

*The other day, there was a cow that wasn't very well down there and the old man, with dementia, rings a vet and says, "I've a cow bad. Will you come out and see her?" So they go out and see this cow, treat the cow – and this was about nine o'clock in the morning. Well, dinnertime, he rings up again because he'd been out and saw this cow on the ground, "I've got a cow that's bad. Can you come out?" "Oh, you've got another one?" So they go out and she says, "Well, this is the cow I saw this morning." "Of course it isn't," he says, "You haven't seen this one before." He got quite aggressive and he ordered her off the place and said he never wanted to see her again ...' National farmer support organisation volunteer*

These interventions had allowed the worker to approach the farms in question and ask if they needed help. In these cases agencies needed to engage in and with the space of the farm rather than waiting for farmers to engage off-farm.

Unsurprisingly perhaps, these examples confirm that the space of the farm is more meaningful to the farmer than public and civic space. It is the arena in which farmers engage directly, such as meeting visitors, or indirectly, through form filling, with civic society and state agencies. It is also the space in which many farmers live out their daily lives and engage as citizens with various agencies and support networks. There is a need to recognise the significance of this space in terms of citizenship and in the provision of care. Yet, as the next section shows, active citizenship policies have tended to emphasise the significance of public and community spaces to support people living with dementia.

## **6. Active Citizenship, Community and Support.**

Forms of active citizenship have been mobilised in various ways to raise awareness of, and provide support for, those living with the early stages of dementia. The idea of community is a central plank in many of these policies. For example, the Alzheimer's Society are encouraging the formation of Dementia-Friendly Communities to provide an inclusive environment for people living with dementia (Bould et al., 2018). These encourage and support people with dementia to participate in everyday life by, for example, using shops and participating in community events. The emphasis is on individuals and communities to act as 'active citizens' by utilising social capital and community facilities to support people with dementia.

Yet many farmers found the idea of community problematic. Some, for example, stated that they had never taken part in community activities and had no desire to now:

*I think I can honestly say to myself, I was lonely, a lonely natured man, self-contained in myself, which didn't lead to any activities of enjoyment. Farming family 8: Farmer.*

Others felt that the social and economic structures of their localities had changed significantly in their lifetimes, which made it hard for them to feel included:

*But back to help in the community, since this village has expanded in the last ten/fifteen years, I hardly know anybody in this village. It's got so big so quick. One time you knew everybody in the village and every kid in the village. All the kids walking up this lane, I don't have a clue who they be. Farming family 4: Farmer.*

*Like I said, they [his parents] were so heavily involved with the church, right, now, since she's been ill, the vicar changed, the new one doesn't come; there's a retired one in the village that does come every two or three months. He's lovely, she likes him a lot. Other than that, people in the village, in the last eighteen months there's been a farmer's wife and her friend [who] came about a month ago for an afternoon Farming family 1: Farmer.*

This is more than a nostalgic yearning for the past. One of the symptoms of early-stage dementia is short-term memory loss, while longer term memory is retained

until the later stage of the condition. Thus recent rural changes are more likely to confuse those in early-stage dementia and consequently make them less willing or likely to engage in community-based activities if they feel out-of-place. There is a need to recognise that community is dynamic and may be understood and imagined in different ways by people with dementia.

Yet, while some farmers seemed reluctant to engage in formal networks of care, and shied away from the socially-centred aspects of support, there was evidence that farmers were willing to help, and accept help from, their neighbours with the farm work. Thus, pre-existing, informal networks were helpful to a degree. These provided practical support for farming rather than providing emotional or personal care.

*As is the case with the farming community, you know, friends and neighbours really, really pulled together, with the farming side of it, not necessarily with the dementia side of it. So that was a help, but things had to change, the farming couldn't carry on as it was doing.* Farming family 9. Daughter of farmer.

*But they all help one another from a farming point of view. Yeah, to keep the farm going and to make sure the animals are okay and everything. They're all very good at that. I mean, farmers are very neighbourly from that point of view, but when it comes down to personal things, I'm not so sure that that is the case.* National farmer support organisation volunteer.

This said, some farmers were reluctant to ask for help from their neighbours and, instead, said that they would prefer to confide in farmers in different parts of the country as this would offer both empathy and anonymity.

*We're [farmer and neighbour] on Facebook all the time and they do understand, especially his wife, she knows what it is to mop up after him, she knows what it is to, you know, so you can talk to them. Not that you do so much. Not that I would say so much as I would to the person on Facebook up the country, because it's your neighbour, and it isn't healthy, that's roughly what. Farming family 1: Farmer.*

While there is a reluctance to join local, formal 'community' networks due to perceived changes in community or a fear that privacy will be lost, existing, local networks provide practical help for daily farming without being intrusive. Some farmers are willing to engage more closely with national support networks as they enable them to talk to other farmers in an anonymous way. This demonstrates that citizen participation is multi-layered and should not simply be equated with what is viewed as local and formal (Closs Stephens and Squire, 2012a; Painter, 2002). It is important, therefore, to understand the life-worlds of farmers and how these influence social citizenship.

## **7. Farming Life-worlds and Social Citizenship**

A focus on the individual citizen draws attention to their life-worlds and the struggles some people face when aiming to engage with society on a daily basis (Philo et al 2003). The emphasis here is on understanding how certain spaces provide opportunities for employment, leisure or social interaction and the ways in which individuals may be excluded, or feel excluded, from participating fully in these daily

activities and spaces (MacKian, 1995). In our study, farmers' lives revolved around the work and home of the farmhouse. It is therefore important to appreciate the significance of this space and the work of farming if we are to understand the relationship between citizenship, dementia and daily life.

The private space of the farm assumed particular significance in the provision of care, at least in the early stages of the illness, but dementia also impacted on the farm business and the way it was conducted in both public and private. Thus, when the illness first became apparent, farmers felt that the space of the farm offered advantages when giving care:

*We were fortunate. Mum, Dad and Auntie lived in the cottage at the end of the farmhouse. So it was literally out one door and in the next. And even that was a big pain on a wet day. But to actually have to travel two or three miles to actually keep an eye on them must put you in a very difficult position because, yeah, you don't want to split that couple up, if they're still a couple ...*

*We used to put mum in the sheep shed ... she used to love lambs ... The sights, the sounds. We think she appreciated it ... But yeah, that was her thing, and we couldn't have done that if she was in a home.* Upland Network Project Manager.

*Yeah I think it, I think if you've always lived in a rural area I think that, I think to be in a different surrounding would be hard. I mean I can remember with mum, we often used to just walk around the fields and just pick blackberries and stuff, and that was fine. But if I tried to take her into town to do some shopping or something that was difficult.* Farming family 9: Daughter of farmer.

As the illness progressed, dementia had a greater impact on farming activities, with consequences for both the business and identity of the farmer. This was often most apparent when the symptoms of dementia were becoming more pronounced but the individual was still attempting to work on the farm in the same way. One farmer went so far as to suggest that his mother's dementia was caused when she stopped farming:

*You see, I blame myself a little bit for this dementia, people say .... you shouldn't do that, but mum, when she was younger, she done bed and breakfast here, let the whole house. She was outside really as well, more than she was in, as in feeding calves; if dad was doing a job she would be there, that type of, she was that type of person, always doing that. Sunday lunch, families, cooking meals, she done it, you know, typical what I would say, traditional farmer's wife. Dad got diagnosed with cancer, she went through six-months nursing him. When he died I said, right, it's my turn, so I took over everything. I took over her bills, I took over – but I thought, it's her time now to do nothing. I still say that was my biggest mistake, by taking everything away, she needed more to think about. Whether it's right, whether it's wrong, I don't know, but she went from being involved in everything to being involved in nothing, and from that moment on is when the dementia started. Farming family 1: Farmer.*

The quote draws attention to the impact dementia has on other family members, especially when the duty of care rested on just one person. One farmer said that as his wife had off-farm employment he felt particularly isolated:

*I got on with the paperwork and the rest of it ... [my wife] was out working late and of course you talk to her, "I don't want to know I've had my day at work" and then there's nobody to talk to ... you know, it's just you and the four walls.*

Farming family 3: Farmer.

A coping strategy used by some was to draw on their farming skills. There was a suggestion that farmers who work with animals were used to looking for non-verbal signs of illness and reacting to them. One farmer said he was used to giving care in an unsentimental way to animals and so he was able to extend this to his wife when she was diagnosed with dementia – his attitude was ‘get on and do it in the best way you can and to the best quality you can’. As the illness progressed, though, dementia had a greater impact on farming activities, with consequences for both the farm business as well as identity as a farmer. This was often most apparent when the symptoms of dementia were becoming more pronounced but the individual was still attempting to work on the farm in the same way. One family member highlighted the dangers this posed:

*There was a period of time where we were just worried. Even when dad was still driving the tractor and you knew that he shouldn't be really, but again, you didn't want to – you didn't feel like you could stop him. There was one time – luckily again, we were lucky, because mum said he used to go over to [...] and have cattle there. He was bringing back bales of hay. I don't know what happened, but anyway, a bale dropped in the middle of [local village], rolled down the hill (laughs) and hit someone's car. It turned out fine, because the people were very nice, it didn't cause much damage, but you just thought, oh,*



*what could have happened. [...] And actually I'm not quite sure how I found out. Because by the time dad had come home he'd forgotten about the incident.*

Farming family 2: Daughter

She was reluctant to stop her father driving the tractor because it connected him to practices of farming, giving him a sense of purpose. Given the sometimes hazardous nature of farming, with opportunities for people to be crushed by animals, fall into slurry pits or be trapped by machinery, it is difficult for colleagues and family members to ensure that individuals remain safe when working alone. One farmer related how she had to take her mother with her when she was working on the farm but even this caused problems:

*But even that gets to a stage that it's not safe to leave them in the Land Rover while you get out to open the gate. Then you need someone to be around all the time and almost dedicated to that person and not doing too much themselves. It's got to be easy tasks. You can't have them in a yard of cows.'*

Farming does not just go on in the space of the farm but is also connected to national and international policy frameworks that farmers are required to engage in as business people and citizens, including DEFRA, the Animal and Plant Health Agency (APHA) and the Rural Payments Agency (RPA). The early stages of dementia often became discernible when farmers had to engage with statutory agencies:

*The difficulty he had was anything to do with all the sort of paperwork and – he always hated it anyway, but as he got worse, that was the difficulty. Things were really getting complicated.* Farming family 2: Daughter.

Keeping up with the necessary administration and paperwork can become very difficult for someone with dementia, as can maintaining standards of animal health and welfare. When farmers were no longer able to undertake this, it fell on other family members who were unfamiliar with the task:

*I remember one time when you said you'd been up all night reading the Countryside Stewardship agreement, because you were worried about meeting all the requirements. And I realised you were feeling such a lot of stress over – because you'd always had dad take care of the farm, and then I realised that you were feeling so much stress over it all'* Farming family 2. Daughter of farmer.

*Well yeah, a good partner as regards husband and wife is, is something that you rely on a hundred-percent. I mean I do – if I hadn't got a good wife, I'm in a very, very fortunate position to have a good wife, two sons that can manage to carry on our lifestyle with difficulty, but without disastrous difficulties. I can't do any better than that [...], can I?* Farming family 8: Farmer.

While the last example highlights the patriarchal roles of family members in running the farm and the ways labour is divided by gender and age (Price, 2012), there was evidence that as the illness took hold, there were changes to gender roles. One farmer, for example, realised that he was not insured to drive his car as his wife, who

had been diagnosed with dementia, had previously organised the insurance. As a consequence, he had to undertake more farm administration. Another farmer noted that her father realised that he needed to undertake more domestic work:

*he didn't know how to boil an egg, he couldn't do anything and then he gradually was helping, sort of covering for mum I suppose really, and then I remember seeing him one day, just sitting at the table looking totally bored, chopping up the fruit into small pieces to make a fruit salad and I could just see his face and he was resigned to the fact that this was a turning point, he was going to have to learn to do these things. He got the recipe books out and he got on with it.*

Farming family 9: Daughter of farmer.

While these examples suggest that changes occur in response to the illness progressing, very few farmers had been proactive in their planning. By contrast, few farmers had planned formally for the eventualities of illness and old age through, for example, gaining Lasting Power of Attorney (LPA) or writing wills. Thus, passing the business on unexpectedly early to the next generation was often a difficult, protracted and financially costly process that interfered with the daily running of the farm. These examples point to an unwillingness to engage with the formal networks that ensure the civic rights of farmers and that, wherever possible, farmers seek to engage mainly in the space of the farm. Initially, many farmers wanted to carry on living their daily lives using family networks to provide care and manage the changing demands of running the business. This highlighted a sense of social citizenship that centred on the space of the farm and being able to engage in the daily practices of farming. Yet, as the illness progressed, they needed to engage more closely as citizens with civil society,

be it through making legal arrangements, working with farming agencies or simply being aware of the wider networks that impacted on the business of the farm. Price (2012, p.371) draws attention to the significance of dwelling, belonging and ritual to farming, suggesting that 'the repetitiveness, from birth, of the lives of farming men within the geographies of home, land and work produces psychological 'props' without which the male, farming [sic] self-withers'. Dementia takes away these props and to understand fully its significance, it is therefore crucial to appreciate how social citizenship centres on the life-worlds of farming space.

## **8. Conclusions**

The idea of citizenship provides a way of understanding dementia in rural places and a framework for providing care for those living with the illness. While citizenship has often been used to describe a political relationship, we side with commentators who have also stressed that citizenship refers to the way people engage with society, its social practices and daily routines (Baldwin, 2008; Clark et al 2016). Indeed, for most people citizenship is social rather than political and refers to an ability to take part in daily activities. This suggests we need to consider individual citizens rather than simply citizenship rights.

Our work has suggested that farmers are disadvantaged when it comes to the formal provision of care: thus, isolation means that diagnosis rates are lower in rural areas and urban-based agencies may struggle to provide care to those in remote locations. If citizens are conceived as the passive receivers of rights, then it might indeed be suggested that farmers lack the rights afforded to their urban counterparts (Tonts and Larson, 2002). While there is certainly a need to improve service delivery in rural places, the idea of citizenship also suggests that the situation is more complex.

Most work on citizenship has focused on public spaces, with less attention given to the ways that citizenship is played out in the home (Chouinard, 2004; Isin and Wood, 1999; Lister, 2007). Yet, the home is an important multi-scalar place that blurs public and private space (Blunt and Dowling, 2006; Brickell, 2012; Lister, 2003) and, in the UK two thirds of people with dementia live at home (as opposed to in institutions such as care homes). There is a need to focus on smaller scale geographies of de-institutional rather than institutional care (Holt, 2010); in other words, focussing on the daily lives of those with dementia, their families and how they cope with condition. This is especially pertinent as people with dementia in rural areas are particularly at risk from loneliness, given that almost 10% of people with dementia leave the house only once a month or less (Smith, 2016). In the case of farming, domestic space is further entangled with its simultaneous use as both a place of business and a place of home, as the appellation farmhouse reminds us.

For farmers, greater attention should be given to the space of the farm as this is the site that forms the basis for citizen engagement. As our work shows, there was sometimes a reluctance to engage with carers outside the farm, be they formal medical agencies or community support groups. For as long as possible, farmers cared for their relatives on the farm and, as much as possible, using the practices of farming. This stresses a need to understand illness in relation to people's 'life-worlds' (Philo et al., 2003) and, as Price (2012) suggests, the cultural and psychological importance of 'the farm' to farming and, in this case, the provision of care. Many efforts to use active citizenship in the provision of care have enrolled ideas of 'community' but for many farmers, this represents a public, distant and often changed space that challenged their securities. By contrast, the farm was a space that allowed them to engage as

citizens, whether well or ill, in the social practices of farming and, as such, to act as social citizens.

At the same time, farmers were required to act within legal-medical frameworks to ensure the running of the farm, which necessitated engagement with outside agencies. Others were also happy to engage with farmers in different localities rather than confide problems with neighbours. The farm too was recognised as a semi-public space where visits from vets, tanker-drivers or neighbours could bring private issues in to the public realm and trigger outside, and often welcome, interventions. The farm, then, is an important local site but one that is linked horizontally and vertically to other people and places (Murdoch, 2000). While citizenship and farming are played out in the everyday space of the farm, it is also a node that connects different places, scales and networks of citizenship (Closs Stephens and Squire, 2012b; Lee, 2008; Painter, 2002). Citizenship offers ways of drawing together the personal and the political; the performative and the structural; the imagined and the material; the nation and transnational; the included and excluded; and the local and the global. In doing so it has the ability to fulfil Paul Cloke's (2006: 26) plea for 'theoretical hybridisation which can combine, for example, the concerns of the cultural turn with those of political and economic materialism.'

## **Acknowledgements**

This work was funded by the Seale Hayne Trust. We are grateful to Ian Sherriff (Chair of the Prime Ministers Rural Dementia Friendly Task and Finish group) and Joanne Jones of the Farming Community Network for help and advice during this project. We

also thank all of our research participants for sharing their knowledge and experience with us so openly and generously.

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