**Keeping up appearances: family carers and people with dementia negotiating normalcy through dress practice**

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**Abstract**

Dress forms part of the taken-for-granted routines that constitute everyday life, but can be dys-rupted in the context of disability – in this case, dementia. Drawing on qualitative research, this chapter situates dress practice as part of how people with dementia and family carers manage the disruption caused by dementia, focussing on the renegotiation of ideas of ‘normality’ and ordinariness. Maintaining ‘ordinariness’ in this context, however, becomes more than just the achievement of continuity, representing efforts to ‘pass’ and manage the public presentation of self in ways that can normalise dementia, and demonstrate how family carers are ‘coping’ and caring adequately.

**Introduction**

Dress forms part of the tacit, taken-for-granted routines that constitute everyday life, but can be dys-rupted (Leder, 1990) in the context of illness or disability – in this case, dementia[[1]](#endnote-1). This chapter situates dress practice as part of managing the rupture caused by dementia in the everyday lives of people with dementia and family carers, focusing on the renegotiation of ideas of ‘normality’ and ordinariness. It begins by exploring interconnections between ageing, dementia, and disability studies in relation to concepts of embodiment, everyday life, and normalcy, before exploring the relevance of dress studies to these discussions. We then draw on ethnographic data from the ‘Dementia and Dress’ study, an ESRC-funded project, described below (Buse and Twigg, 2014; 2015; 2016). Within this data, dress is situated as part of renegotiating ‘ordinariness’ and ontological security through daily routines and practices, and maintaining continuity in appearance. We go on to consider how dress also becomes incorporated into efforts to ‘pass’ and manage the public presentation of self in ways that can normalise dementia, and some of the tensions embedded within this (Goffman, 1963). The chapter concludes by arguing for the potential of dress as part of efforts to foreground embodiment and the everyday within disability studies, acting as a ‘lens’ for tracing how ‘corporeal norms’ are negotiated in everyday life. We further argue for the extension of a ‘carnal politics of the everyday’ (Paterson and Hughes, 1999) to dementia studies, with attention to dress as part of this.

**Embodying ageing, dementia, and disability studies**

The fields of disability studies and social gerontology have developed separately, so that discussions of later life are generally absent from collections on disability, and vice versa (Oldman, 2002). Yet it is argued that the social model of disability has much to contribute to the study of ageing, in terms of understanding the experiences of older people with disability, addressing issues of ageism, the physical environment, and offering a model for collective action (Putman, 2002). Similar arguments have been made for the application of the social model of disability to the experiences of people living with dementia. In relation to dementia, this extension has proved significant in challenging the overreliance on biomedical/psychological models, allowing for a greater recognition of the socio-cultural context of the condition (Downs, 2000). The ‘social model of dementia’, led by the work of Kitwood (1997), aims to focus on capabilities instead of losses, recognising the deleterious impact of social discrimination and marginalisation, and emphasising the importance of listening to the voices of people with dementia (Gilliard et al., 2005). The social model of disability also underpins recent thinking about collective action among people with dementia, resonating with the citizenship agenda in dementia studies (Bartlett and O’Connor, 2007). This agenda aims to politicise dementia studies, drawing attention to the rights of people with dementia as equal citizens, and instances of discrimination. However, there are concerns that an emphasis on dementia activism may marginalise those who are not verbally fluent, visible, and confident (Bartlett, 2012a).

In both ageing studies and disability studies, there has been a shift towards the recognition of the role of embodiment as part of understanding everyday lived experiences. Both the social model of disability and social gerontology in earlier stages tended to marginalise the role of the body, preferring to foreground the social and cultural determinants of old age and disability. More recent work, reflecting wider developments in body studies (Shilling, 2013; Crossley, 2001), has brought the body fully into view, emphasising the ways in which it is culturally constituted, and exploring the complex interplay of factors – social and physiological – in the constitution of age and disability (e.g. Davis, 1995; Featherstone and Hepworth, 1991, Gullette, 1997; Gilleard and Higgs, 2000; Hughes, 2007; Paterson and Hughes, 1999). For example, Kumar (2004: p.31) describes embodiment as ‘the site where ageing, disability and masculinity intersect’. Her work explores the disruption of ontological security following the onset of a disability in later life, and the embodied strategies older men deploy in order to maintain continuity of self. Other research has highlighted interconnections between ageing and disability in relation to changing experiences and awareness of the impaired body over the life-course (Deegan, 2010; Williams and Barlow, 1998).

Dementia studies is also beginning to incorporate concepts of embodiment as part of understanding the everyday experiences of ‘living with’ dementia (Martin, Kontos and Ward, 2013). A focus on embodiment is being used to extend arguments for the citizenship of people with dementia, critiquing notions of citizenship and personhood that rely heavily on language and cognitive ability (Boyle, 2014). Kontos (2004) argues that people with advanced dementia can demonstrate intentionality and agency through embodied, habitual actions that reflect habitus and social location. Taylor (2008) challenges the focus on the capacity of the person with dementia to recognise and name family members, arguing that interpersonal connections continue to be enacted at an emotional and embodied level. Research by Phinney and Chesla (2003) has also highlighted the significance of the ‘lived body’ for understanding experiences of dementia, though their work by contrast emphasises the way that dementia disrupts everyday embodied practices and relations to objects.

Through attending to lived experiences of bodily impairment, this body of work draws to attention to how dynamics of normalcy are negotiated in everyday life. In disability studies, research has explored how people maintain a sense of ordinariness (Coleman-Fountain, 2016) or ‘feeling normal’ in the face of bodily impairment (Deegan, 2010). This includes the day-to-day management of the impaired body, and creating new ways of ‘doing daily living’ (Hansen and Philo, 2007). This research parallels literature in the sociology of health and illness, which highlights efforts to retain a sense of ‘ordinariness’ and continuity (Prout, Hayes and Gelder, 1999; Gregory, 2005) in the face of the ‘biographical disruption’ caused by chronic illness (Bury, 1982). However, disability studies literature also demonstrates how a sense of ‘feeling normal’ fluctuates across different contexts (Deegan, 2010), as disabling spaces and social interactions ‘remind’ the person of bodily impairment, reflecting Leder’s idea of bodily ‘dys-appearance’ (Paterson and Hughes, 1999). This includes the pressures to normalise the impaired body in everyday spaces in response to the non-disabled gaze, managing bodily appearance and movements in order to ‘pass’ and ‘perform’ as normal (Hansen and Philo, 2007). As argued by Paterson and Hughes (1999: 608), oppression is not simply produced at a structural level, but ‘is made manifest in corporeal and intercorporeal norms and conventions’ which are enacted within ‘everyday encounters’.

Such concepts of normalcy also hold significance for dementia, which Schillmeier (2014: 44) argues ‘troubles the normal, the given and expected personal and social life’, disrupting affective and embodied relations to objects and people. In this way, he suggests, experiences of dementia can draw attention to normalcy as a mode of social ordering and an ongoing collective achievement. Dementia also raises particular issues concerning pressures to ‘normalise’ the body, including dress and appearance, to which we now turn.

**Dress practice, normalcy, and normalisation**

Dress is central to the social experience of embodiment, providing a direct interface between the body and public realm. Entwistle (2000) describes dressing as a ‘situated bodily practice’, involving ‘both an intimate experience of the body and a public presentation of it’. In the context of disability, everyday dress practices can become disrupted, providing challenges both in terms of the physicality of dressing and the symbolic transgression that assistance with dressing entails (Hayman, 2009). Research on disability has highlighted people’s capacity to identify strategies and creative individual solutions for managing dress, thus retaining possibilities for a continuity of identity and self-expression (Linthicum, 2006; Hayman, 2009). For instance, Hayman (2009: 630) gives the example of a male participant ‘casually slinging’ an expensive suit jacket on the back of his power-chair when he was in the workplace, creating the image of smart, masculine dress, while avoiding the difficulties of putting the jacket directly on his body.

Dress is also entangled with issues of normalcy and normalisation. Historical research on dress and learning disability has highlighted the stigmatising nature of institutional dress, with unfashionable and ill-fitting garments signifying difference/disempowerment and constructing disabled people as ‘asexual’ (Linthicum, 2006). In contrast, the normalisation movement called for the integration of people with learning disabilities into ‘normal’ social life, emphasising the importance of maintaining positive social roles for devalued groups (Wolfensberger, 1972; 1983). Dress and appearance were emphasised as part of maintaining a positive social image, and avoiding an appearance that would mark the person out as deviant. More recently, though, the movement has been subject to critique for presenting an over-normalised model of behaviour that imposes standards of conformity as a ‘condition of acceptance’ (Yates et al., 2008: 249). Research on learning disability and embodiment has also highlighted tensions around choice and control in an institutional context, with a tendency of staff to interfere with the person’s decisions around dress (McCarthy, 1998).

Dynamics of normalcy and efforts to ‘pass’ (Hansen and Philo, 2007) are also played out in relation to everyday dress practice in disability. Fashion and dress, as Simmel (1904) argued, embody a fundamental tension between a desire to fit in, and a desire to emphasise uniqueness and self-expression. Dress can thus be used to reveal, as well as to conceal, aspects of identity, including ones in relation to class, gender, sexuality, and disability (Banim, Green and Guy, 2001; Woodward, 2007). These dynamics have been explored in the context of disability and illness with Van Wersch (2001), for instance, examining how women negotiate decisions around revealing, versus concealing, the impaired body through dress and prosthetics. Linthicum (2006) has shown that there is a different relationship to dress and visibility among individuals with a life-long disability compared with those who are more recently disabled. She found a stronger emphasis on dress as a way of camouflaging impairment among the more recently disabled, and a greater focus on self-expression through dress among those with a long term disability.

Like intellectual disability, dementia raises issues around choice and control in relation to dress and the normalisation of bodies in both institutional and home contexts (Twigg, 2010; Buse and Twigg, 2014, 2015). Dress practices can be disrupted in dementia, with difficulties relating to sequencing, recognition, and concentration, as well as managing fastenings and difficult garments (Feyereisen et al., 1999). This can create challenges in living up to social norms of acceptable dress which can extend beyond the domestic context, disrupting attempts to pass in the wider community. In an article John Keady co-authored with his father who has dementia (Keady and Keady, 2005: 36), his father recounts the embarrassment caused by incorrect dress in public spaces, realising he had been ‘wearing the wrong shoes for several months’ and ‘having a panic attack in a department store’s public toilet when I put my underpants on back-to-front and realised what I had done’. Bartlett’s (2012b) work on dementia activism shows the power of correct dress – in her case the wearing of a suit by a man – in affecting how the person is seen, allowing them to continue to draw on the embodied status that suits convey (Breward, 2016) and to counter preconceptions of people with dementia. It is these issues around constructions of ‘normalcy’ and ordinariness through everyday embodied practice that we will now focus on, turning to the findings of the Dementia and Dress study.

**Introducing the study**

Dementia and Dress was a two year ESRC funded study conducted between 2012-2014, exploring the role of clothing and dress in the everyday lives of people with dementia, family carers, and care-workers. The research was conducted across three care homes and fifteen domestic households in Kent, UK. The sample included thirty-two case studies of people with dementia: fifteen living in their own homes, and seventeen in care home settings. People with dementia were sampled purposively to explore differences relating to class, gender, and stage of dementia, and included nine men and twenty-three women from different occupational backgrounds and at different stages of dementia (from mild to severe). The study also included interviews and observations with twenty-nine family carers and relatives, and twenty-eight members of care home staff. This chapter focuses on the accounts of family carers and people with dementia, focussing in particular on the domestic context and the dynamics of everyday life.

Data were gathered using ethnographic methods including observations, qualitative interviews, and visual and sensory methods such as ‘wardrobe interviews’ (Banim and Guy, 2001). This involves interviewing the person alongside their wardrobe, using clothes as material prompts for eliciting discussion. In domestic households, participants generally chose to conduct wardrobe interviews jointly with family carers, enabling the carer to provide support during the interview, and facilitating direct observation of interactions and negotiations around dress (Valentine, 1999). Observations facilitated inclusion of people with more advanced dementia who were unable to participate in more formal interviews (Hubbard et al., 2003). The study received ethical approval from the Social Care Research Ethics committee. Every effort was made to involve the person with dementia in the consent process, explaining the study verbally as well as using adapted information sheets with visual images. For people unable to give informed consent, we sought the advice of a personal consultee, generally a family member. For all participants, consent was treated as ongoing and the respective researcher responded to verbal or non-verbal indicators of assent or dissent (Black et al., 2010).

**Daily routines, dress, and negotiating ordinariness**

Dress and dressing are part of the ‘day-to-day activities’ that underpin daily life, actively producing a sense of the ‘normality of the ordinary and the everyday’ (Gregory, 2005: 374). Dementia can disrupt these taken-for-granted routines and ‘body techniques’ (Mauss, 1979). As one family carer, Cora, explains regarding her husband:

I don’t think he could do the... the bow [on shoelaces] now because he has a job with his dressing gown tie […]. Some things I think would come automatic, like playing the organ but no, it’s completely gone and yet he’s played it for what? Thirty-five years and all the chords he knew off by heart, they’ve gone. You know, because it’s immediate memory.

As Cora describes, the embodied tacit knowledge involved in dressing becomes disrupted in the context of dementia, and clothes as material objects are no longer ‘ready-to-hand’ (Heidegger, 1962). Dress can therefore bring the impaired body and a sense of ‘feeling disabled’ to the ‘forefront of everyday life’ (Deegan 2010: p.25). For Joe, difficulties with dressing prompted reflection on his decreasing cognitive and physical abilities: ‘Invariably now, well you see I can’t do it. I used to, used to be no problem at all’. As found by Kabel and colleagues (2016), aspects of clothing such as shoelaces, socks, and fastenings can be particularly challenging in the context of disability, posing ‘apparel related barriers’ (p.2186) which contribute to disablement.

Dementia also alters the temporality of dressing. Family carers described this in terms of ‘slowing down’, and altering taken-for-granted bodily movements. As one family carer, Jane, said: ‘everything takes so long because it’s slow motion’. Another couple joked:

Barbara:…if we are going out, I should say it takes two hours to get both of us ready. […] It takes an hour and half to get him ready, and ten minutes for me [laughs].

## Joe: Used to be the other way round!

As Phinney and Chesla (2003) also found, the flow of taken-for-granted activities is disrupted by dementia, with bodily movements becoming halting and tentative. Research on physical disability similarly highlights concerns with timing and slowness, which signify bodily difference, with everyday activities like dressing perceived to take ‘longer than is “normal” or acceptable’ (Hansen and Philo, 2007: 498). Patterson and Hughes (1999: 605, 607) argue time ‘is the primary criteria of exclusion and discrimination’, with the status of social competence withdrawn from bodies that fail to live up to ‘norms of speech, timing and movement’.

People with dementia and family carers deployed a range of practices to manage these temporal disruptions, engaging in the ‘embodied art of managing the time, space and speed realities of “doing” daily living’ (Hansen and Philo, 2007: 497). Adjustments to daily routines included planning ahead and laying out clothing the night before as well as allowing additional time, particularly if going out. The potentially disrupted and fluid character of such activity is well captured by Davies’ (1994) concept of ‘process time’ which reflects the unpredictable, non-linear nature of care processes, their interweaving with the body. As a result, the act of dressing was felt to be something which could not be rushed. This slower and more uncertain temporality of dressing seemed more accepted by retired couples, perhaps reflecting changing meanings of time in retirement, associated with a sense of freedom from fixed routines and ‘slowing down’ (Roche, 1989; Tsuji, 2005). As retired family carer, Fred, claimed: ‘time doesn’t matter’.

To a significant extent, ontological security rests on the familiarity of daily routines, repetition, and rituals (Giddens, 1992). For people with dementia, maintaining these can be important to coping with the condition (Keady and Keady, 2005), and retaining a sense of normality. In the face of the disruption of everyday temporality, spousal carers tried to embed dressing into new routines which were relational and embodied. Female carers in particular talked about washing and dressing alongside their husbands, as one woman, Barbara, said: ‘it’s quicker […] than trying to wash in relays, because he keeps calling me. I wash my face and then go and run some hot water and wash the rest of him’. Spousal carers often re-embedded dressing within other household routines and activities that were associated with relaxation and security such as reading or watching television, as Cora (family carer) describes:

And then usually help him undress in the evening. We go in there together, don’t we, and I put my dressing gown on as well at about eight and then we come back and watch something on the telly [television].

These routines reconstitute a sense of familiarity and continuity with existing relationships**.** However, other carers felt that the unpredictable bodies of relatives with dementia were less amendable to being routinised, as family carer, Grant, explained: ‘you try and keep them in a routine but it just doesn’t work. You know, you have to go with the moods’. Temporal disorientation means that routines can be disrupted and difficult to maintain (Bartlett, 2012a), with carers describing relatives with dementia who would go to bed in the afternoon or get up in the middle of the night and start dressing, often putting on clothing in the wrong order.

For some family carers and people with dementia, helping the person to continue dressing independently was described as an important part of keeping things ‘normal’. This was facilitated by the management and spatial ordering of the material environment, including the micro-space of the wardrobe. As argued by Woodward (2007), ordering our wardrobes can be a strategy for the ordering and management of our everyday lives. In the context of dementia, family carers took on the responsibility of this, placing frequently worn ‘habitual’ clothes to the front of the wardrobe so they were accessible, but also circulating the order of clothing so that the person did not wear the same thing every day. Family carers also engaged in ‘aesthetic ordering’ (Woodward, 2007), placing items of clothing together, co-ordinated in terms of colour and style. As family carer Greg said, he and his wife had ordered his mother in law Pearl’s wardrobe ‘to help her make choices and also in the drawers put colour-co-ordinated if you like sweaters and t-shirts that matched’. Pearl agreed this helped make dressing easier to manage: ‘they’ve arranged all my... my clothes, you know, in colour co-ordinate…All the colours that go with each other on the bottom so that I don’t have to reach up’. Ordering the wardrobe aesthetically makes dressing easier, enabling the person to ‘get it right’ (Woodward, 2007: 44). Such strategies of ‘tailoring’ and adjusting the home environment to disability, act as ‘recipes which create and maintain situations for “feeling normal”’ (Deegan, 2010: 33). Yet such ordering can also mean that the family carer has taken over aesthetic decisions involved in self presentation, limiting the agency of the person with dementia in terms of their dress and appearance.

What constitutes ordinariness or normality is differentiated, however, according to gender and generation. In relationships which involve a wife caring for her husband, assistance with dress was more in keeping with traditional gendered roles, which often continue into retirement (Loretto and Vickerstaff, 2012; Szinovacz, 2000). Men with dementia spoke more readily about being assisted with dress, at least by their wife, saying things like ‘I couldn’t manage without her’ or she ‘looks after me on that score’. In contrast, women with dementia tended to minimise or dismiss any difficulties; as one woman said, they are ‘just part of life’, emphasising the ‘ordinariness’ of these experiences (Prout, Hayes and Gelder, 1999). Another woman, Diane, dismissed such concerns as reflecting her husband’s inability to cope with illness: ‘I don’t let it spoil my life – I try not to. It affects my husband more than it does me but […] his family doesn’t do illnesses very well.’

In relation to laundry and shopping, the pattern of activity was affected by earlier gendered roles. As family carer Jane explained, she had ‘always done the washing and ironing’; while Cora described how her husband has ‘always left [clothes shopping] to me really.’ Therefore, such caring activities are subsumed within gendered family practices ‘seen as just part of the “normal” task of running the home’ (Gregory, 2005: 374). In contrast, men taking on these roles was frequently viewed as a disruption of normal life for both parties. George stated that he had only taken on laundry activities ‘since the illness’ and ‘I’m not doing it because I particularly want to, or enjoy it.’ His wife Diane, by contrast, saw his taking on these tasks as unnecessary interference: ‘he just gave up work early and he just took over.’ Nonetheless, some men would get their wife or mother to help with laundry activities, as a way of maintaining normal gendered routines. Grant tries to involve his Mum in ‘washing day’ on a Thursday, although her twin tub no longer worked and he had to take the fuse out of her iron for safety: ‘we just go through the pretence and I bring it all home and do it.’ Housework had been important to his Mum, who even ‘used to iron handkerchiefs’, and he felt that involvement in these activities helped her to ‘keep in a routine.’

In intergenerational and cross-gender caring relationships, assistance with dress that required intimate hands-on care and exposure to the unclothed body was experienced as a disruption of the ordinary, transgressing norms of family relations and body privacy (Twigg, 2000; Isaksen, 2002). One family carer, Grant, described the difficulties of assisting his Mum with dress:

The main problem I have is getting her to change, and being... like her son I can’t get too involved. […] She doesn’t change very often, and I was trying to get her to change her underclothes, and she ended up with her dirty clothes on and still two pairs of clean drawers on top of that. And I’m trying to do it all through a closed door.

Grant tried to reassert boundaries of bodily privacy through reconstructing material and spatial boundaries, as he says above: ‘I’m trying to do it all through a closed door’. This was in contrast with couples, where assistance with dress was consistent with relations of intimacy. As family carer, Cora, said: ‘We know each other so well. We’ve been together thirty-seven years and neither of us are embarrassed at all’. Her husband, Douglas, agreed: ‘You can’t be shy about it’.

The discomfort of assistance with dress could be confounded by the transgressive nature of dealing with gendered garments. Grant describes the embarrassment of ‘bra shopping for the first time in my life’. Other male carers (including husbands) described the particular difficulties of tights and bras. This partly related to the physicality of manoeuvring them onto the body, involving gendered practices and body techniques, but it also related to the way handling such garments was transgressive for men. As one family carer, Frank, said: ‘I mean all these are things I never even thought of: gussets’. Taking on a caring role could be discontinuous with men’s earlier histories and gendered identities. As family carer, Grant, who had originally worked as a labourer, explained: ‘[this] isn’t my game at all, nursing...You know, it isn’t my history.’

Male carers engaged in different strategies for managing role reversals and transgressions, in order to re-establish a sense of ordinariness (Gregory, 2005). Some male carers resigned themselves to new roles. As Grant said, regarding his experience of bra shopping: ‘that was quite embarrassing, but I got over it in the end’. He resituated his new role within normal family relationships of caring, saying ‘this is the family, mate! You know, there isn’t anyone else’ and there was ‘no choice’ in terms of his ‘conscience’. In other cases, carers made material adjustments to the dress of the person with dementia. A number of male carers, for example, switched to dressing their wife or mother in trousers to save ‘messing about with tights’. Such material adjustments, however, raise questions regarding continuity of embodied identity, to which we now turn.

**Maintaining familiarity and continuity through dress**

Maintaining a sense of normality and ‘ordinariness’ was not only a matter of temporal routines and practices, but also of maintaining continuity in the person’s appearance and personal aesthetic (Woodward, 2007). Dress practice therefore becomes significant as part of everyday ‘acts of construction and reconstruction’ which ‘create a continuous sense of ontological security; meaning a desire for continuity of self-identity and the reliability of social life over the life-course’ (Gregory, 2005: 374). Family carers generally described this continuity as the most important thing for them. As family carer, George, stated: ‘she’s always dressed smartly so what matters to me, I suppose, is that she continues to do so.’ Similarly, family carer Jane stated that what was most important to her was ‘making him look as smart as possible, because he has always been a very smart man’. As we have discussed elsewhere, dress and appearance are significant in terms of maintaining continuity of self at an embodied level, entangled with attributes of personal and social identity (Buse and Twigg, 2015) and embodied biographies (Buse and Twigg, 2016).

People with dementia frequently described the continuing importance of their personal style or aesthetic (Woodward, 2007) or their ‘appearance signature’ (Ward et al., 2014). They often retained a strong sense of the styles, colours and textures that were – or were not – ‘them’. These notions of personal aesthetic also related to dimensions of social identity. For women, whether they were a skirt or a ‘trouser person’ could be important, affecting the wearer’s ability to enact a particular form of gendered identity, shaping the potential of the body to move in particular ways (Twigg, 2013). As one woman said: ‘I could never feel comfortable going out in trousers’, while another described herself as ‘more of a trouser person’. For many men in the sample, it was a sense of smartness that was most important, for instance, one man described how he had ‘just felt right’ wearing a suit tie and jacket. This sense of what ‘feels’ right relates to the ‘notion of aesthetic fit: the wearing of clothes which are “you”’ (Woodward, 2007: 73). Clothing can therefore retain a sense of familiarity and ‘feeling normal’ (Deegan, 2010) at an embodied, tactile level; as one woman with dementia said: ‘I think it’s what you get used to and what you like…what you feel comfortable in.’

When people with dementia could no longer maintain their dress and clothing choices independently, family carers became involved in ‘curating identity’ on their behalf (Kricton and Coch 2007). Such practice illustrates embodied identity as mutually constituted and intercorporeal, as a ‘becoming-in-the-world-with-others’ (Hughes et al., 2005), challenging notions of the ‘normal’ body as autonomous and bounded (Weiss, 2009). Dress practice is always relational and intersubjective, shaped by the anticipated responses and feedback of others (Banim, Green and Guy, 2001). In the case of dementia this becomes more pronounced, with decisions about dress becoming a negotiation between family carers and the person with dementia, blurring their personal histories and aesthetics, locating dress choices in the space between ‘one’ and ‘one another’ (Jackson, 2012). Making decisions about dress on someone’s behalf involves drawing on tacit, biographical knowledge that is embedded in shared histories, as Ellie (family carer) suggests:

I think it’s important to me because I know, I understand, it’s important to her. […] I understand she’s a proud lady and, you know, I’ve grown up with her always having certain routines and she would always explain to me as a little girl, you know, she always had her lipstick on and the way she did her hair and the way she dressed. It was always important to her. So I’ve just, you know, I’ve taken that on board, I think, and I just do it instinctively, to be honest.

Maintaining embodied routines of dress and appearance management can become ‘instinctive’ through the depth of connection to the person. As the extract relates, the little aspects of someone’s dress could be most significant – the fact she ‘always had her lipstick on’, or ‘mum always has tights’, or a partner ‘always likes to have his wallet’, or always wears a watch. This extract also illustrates how maintaining continuity of dress reaffirms a version of the person long-established in the mind of the carer, associated with their ‘recognition’ of the person (Taylor, 2008).

Maintaining continuity in appearance was also important for family carers because of the way in which dress stands for the person (Ash, 1996), and their relationship to them. In the face of rupture caused by dementia, clothing can be a way of holding onto the person, and managing biographical disruption (Bury, 1982). As family carer, Mark, explained: ‘because their personality’s changing anyway and if you change the way they look […] I think you’d be coping with losing another part of them.’ For him and for others in the study, dress could come to symbolise a continuing sense of normality and ordinary life:

…you’re thinking *if mum looks normal, if we’re keeping it normal we’re keeping life normal and it’s not as bad as it is.* It’s slightly denial but it’s also... […] it makes you feel I suppose better with *them* that you’re not... it’s not as – I don’t know – hopeless a situation as it could be where you just give up.

As Mark describes, maintaining his Mum’s appearance became a way of keeping life normal and retaining a sense that things were ‘not as bad’ as they might seem, staving off fears of a situation that was ‘hopeless’. Maintaining her dress was also a way of not giving up on his Mum and his relationship to her. On the other hand, some carers recognised that clothes no longer mattered to their relatives, or indeed to them, but that they remained significant to the wider family. As family carer, Annette, explained: ‘once they get to the stage that Mum’s at, it’s almost what’s more important to the family rather than what’s more important to the person’.

Clothing could disrupt as well as sustain a sense of continuity and familiarity. People with dementia sometimes ceased to recognise clothes belonging to them and refused to wear them, illustrating how the familiar and everyday can become ‘uncomfortable and unwelcome’ (Longhurst, 1994: 219). One woman, Diane, had amassed a pile of seventeen pairs of jeans in her bedroom, explaining to the researcher ‘I don’t think they’re are mine’ and ‘I don’t know when I last wore jeans’, whereas her husband insisted ‘they are hers’. This was particularly the case with clothes that were bought more recently and held less emotional salience – Diane provided detailed accounts of clothes worn for holidays, graduations, and family weddings, while forgetting the jeans bought more recently.

Changes in the person’s clothing and appearance could be viewed by family carers as marking the progression of dementia. Sometimes families reported that the person’s clothing choices changed following the onset of dementia, for instance, wearing more ‘garish’ colours and styles. Often family carers reported a loss of interest in or ability to maintain appearance, as Ellie said regrading her Nan: ‘She was very proud of how... how she appeared…Not anymore at all.’ Embodied changes associated with the progression of dementia could also lead to family carers making adaptations to dress. Some family carers introduced jogging bottoms for men rather than smart trousers, because they supported ease of dress. Jane had started buying jogging bottoms for her husband instead of his usual jeans or smart trousers because he had incontinence and struggled with zips and buttons. She recalled that ‘when he was younger he wouldn’t have worn jogging bottoms – he wouldn’t have been seen dead in them!’ but now ‘I’ve got used to seeing him with his trainers and his joggers.’ Fred had switched to dressing his wife Alice in trousers because ‘it’s easier for me to dress her’, though he would still help her dress up and wear skirts for special occasions: ‘it’s nice to see her when we go out when she is dressed up, if you know what I mean?’ These changes were made for practical reasons but undermined a continuity of identity and family relationships and signalled further stages in the decline of the person with dementia.

The disruption of continuity in appearance and dress could be particularly stark following transitions to care, and family carers would sometimes remark that the person looked ‘completely different’ when they visited them in a care home. Some family carers would try to pass on detailed information to enable care-workers to continue to curate person’s identity, and we observed a number of examples of good practice in this (Buse and Twigg, 2015; 2016). However, families also described instances where the person was dressed in crumpled clothes or in someone else’s clothes. These instances were hurtful because they were seen as a betrayal of the person’s embodied identity, a ‘curtailment of self’ (Goffman, 1968: 24) through the failure to maintain personalised clothing which is a fundamental part of the person’s ‘identity kit’ (p. 29). As family carer, Melissa, describes:

I’ve never seen my dad scruffy. Never. Until that day I turned up in the home and he’s sitting there in screwed up clothes which really hurt me because I’m not used to that – not at all.

Here, Melissa’s Dad’s ‘standards’ of smart, well-ironed clothes were disrupted in the context of care. Such judgements about acceptable and normal dress are read in the context of embodied biographies and ‘standards’ of dress which are generational, gendered, and classed, as discussed below. The laundry regime in care homes also limited the range of fabrics which could be brought into care, with fabrics like ‘tweeds’, ‘silks’, and ‘proper woollens’ being particularly discouraged. Such fabrics can convey comfort and familiarity at a tactile level, as well as ideas about ‘quality’ fabrics being embedded with the habitus and identity of middle-class participants. Therefore, possibilities for maintaining continuity of self associated with ‘normal life’ and ontological security at a tactile, embodied level can become limited following transitions to care and the progression of dementia.

**Passing, stigma, normalisation**

There was a tension in the interviews between the desire to respond to the wishes of the person with dementia, and what were seen as traditional performance norms in relation to dress. Dress is part of the micro-order of social life and dressing inappropriately can incur moral judgements (Entwistle, 2000). In the context of later life, these judgments can take on a new meaning, with ‘slippages of dress’ such as tears, stains, or drooping hems becoming interpreted as signs of wider mental or moral failure, pointing to the dereliction of age (Twigg, 2013). Dressing as one gets older, therefore, can become a process of staving off such dereliction. But this can be increasingly challenging in the context of dementia where odd, discordant, or bizarre dress can signal a reduced, and potentially stigmatised, social status. Stigma here can also be associative (Goffman, 1963). One woman described how when she takes her friend Deirdre out shopping, who tends to wear the ‘same old tatty clothing’, she was concerned that ‘people seemed to look’ and might think ‘poor old lady’, although Deirdre herself ‘doesn’t care’. Mark discussed how ‘little slips’ in appearance – incorrectly applied make up, incorrect or uncoordinated dress – become read as signs of dementia and the progression of the condition. In contrast, Mark suggests that a ‘normalised’ appearance can be a way to avoid the stigma associated with the condition: ‘I think it normalises in a strange way and makes dementia more acceptable, because I still don’t think it’s acceptable by a lot of people.’

Dress therefore becomes part of the hidden labour involved achieving the appearance of ‘normalcy’ (Deegan, 2010) and maintaining a public ‘front’ (Goffman, 1969). For some people with dementia, maintaining an appropriate presence in the wider public world remained important. Pearl described how this still mattered to her, saying ‘well I wouldn’t like to go out looking, you know, a mess’ and that if ‘you didn’t think that you looked very nice you would feel people were saying, “Oh look at her”’.Similarly, Kathy described how she was ‘very particular’ about her appearance ‘even if you’re going up the shops’ or ‘going to the doctor’s’. Kathy described her appearance as ‘the thing that I am most particular with…and my housework’. Her linking of the two spheres of dress and housework, and her close association of herself with both, reflected classed standards of neatness and cleanliness, which have traditionally been important for working-class women in achieving ‘respectability’ (Skeggs, 1997). Twigg’s (2013) study of women, dress, and age similarly found that working-class women in their seventies and eighties emphasised the importance of neatness and cleanliness in dress above considerations of fashion or style.

Avoiding the dereliction of age was also linked to the stigma associated with ‘leaky bodies’ and incontinence (Lawton, 1998), which disrupt the normative body as ‘clean and proper’ (Paterson and Hughes, 1999). Family carers often emphasised the importance of clothes being ‘clean’ and ‘fresh’. This not only related to appearance but to anxieties about smell, that most pervasive and insidious of presences, with its capacity to cross boundaries and evoke hidden transgressions (Classen, Howes and Synott, 1994). As Barbara said: ‘My main concern is that he is clean and fresh smelling, because that can be offensive.’ Smell epitomised the dereliction of age. As Cora explained: ‘I can’t bear an old man to smell an old man smell so I never ever let him get to that stage’. This was partly about maintaining the person’s earlier ‘standards’ of dress and laundry, but it was also about protecting them from the exposure of bodily betrayals (Isaksen, 2002).

Adaptive clothing was sometimes described as a solution to help avoid bodily betrayals. Jane had encouraged her husband to wear track suit bottoms which were easier to manage, because she said: ‘I would hate for him to wear trousers with zips and buttons and have an accident’ in public. On the other hand, some people with dementia avoided ‘simplified’ clothing because it held associations with frail and disabled bodies. Joe refused to wear the Velcro shoes someone had passed on to him because he felt they were ‘old people’s shoes’: ‘I don’t want people to think “oh there’s the old boy”’. Velcro has been argued to signal disability and mark the person as different (Linthicum, 2006). Joe also resisted his wife’s suggestion of tracksuit bottoms because: ‘I feel an idiot wearing a tracksuit now when I can’t even walk across the room!’ Other participants resisted the idea of adaptive clothing, concerned that it might convey a ‘uniform’ or standardised appearance which conveyed the ‘look’ of dementia, creating rather than avoiding a stigmatised appearance.

The intersection of the physical environment with dress practice provided further barriers to the maintenance of a ‘normal’ appearance and bodily performance. As described in the example by Keady and Keady (2005), clothes shopping could become difficult and embarrassing in the context of dementia. Gender coded dressing rooms made assistance with dress difficult when out shopping, as family carer Greg recounted:

… she went back into the changing room and [...] she hadn’t come out and I said to the girl, I said, “There isn’t anybody... Can I go in because I’m not sure what on earth she’s doing?” and I went in and she was wandering around because she couldn’t find where she’d left her original trousers. […] I think it did knock her confidence that, you know, she... she was embarrassed to come out and say, “I can’t find my trousers.”

This reflects the findings of previous research on shopping, in which fitting rooms were a ‘major barrier’ for people with disabilities (Macdonald, Majumder, and Bua-Iam, 1994). Such incidents disrupt efforts to ‘pass’ (Goffman, 1963), bringing awareness of impairment to the fore (Paterson and Hughes, 1999). Other family carers talked about a lack of available gender neutral toilets when out shopping or in public. Tom ‘used to love shopping’ but his wife Jane tends to go shopping for him now because ‘I can’t go in the gents with him, it’s difficult’.

The reach of the public gaze and judgements about dress was not limited to public space but extended to practices in the home. Home is classically regarded as private space, though its privacy is structured spatially and temporally (Twigg, 1999). This structuring is reflected in dress practices, with different forms of dress and undress being thought appropriate for different times of day and different social circumstances. The coming of disability can disrupt this ordered privacy, exposing patterns of behaviour previously hidden. Barbara recounted how her husbands’ tendency to walk ‘around in underpants in the house is a bit embarrassing’ when visitors come to the house. Her efforts to encourage him to dress sometimes sparked off an argument: ‘I’ll say “go and shut yourself in the room or put your trousers on”’. Mark describes how the coming of carers to help with his mother meant that dress in the home came to conform more nearly to public standards: ‘you do set to conform, even within the house’ when ‘other people are coming through*’.*

Dress was not only viewed as something which incurred moral judgements on the person with dementia, but was also experienced by family carers as a comment on their own care practices. As family carer Frank said, maintaining his wife’s appearance was important to him because ‘it’s a reflection on me as well, you see.’ This response appeared more significant for male carers, perhaps reflecting the contrast with their earlier gendered roles and a greater need to prove they were able to care adequately. Frank describes other women at the day centre whose appearance was not so well maintained and were ‘always in the same outfits’, reflecting that ‘some men haven’t got any idea of how to dress a woman.’ Family carer Mark similarly described appearance as a sign that the person was well cared for and stated ‘there was always that element of, you know, nothing’s going to slip.’

Clashes and tensions sometimes emerged in efforts to maintain a normalised appearance. Mark described disagreements when his father had put on clothing which was ‘muddled’ and he would encourage him to change. He reflected ‘I don’t know whether it’s the right thing to do’, accepting that his father being incorrectly dressed was embarrassing for him and not his father. A focus on maintaining a normalised appearance can also undermine the special meanings that certain items of dress can have. Torn and old clothing, for example, can seem to signify dereliction or neglect, but they may also have personal and biographical significance for the person with dementia. Jane had a number of disagreements with her husband Tom over his old work clothing, which he used to wear on site as a builder. Jane regarded these clothes – torn and marked with plaster – as acceptable for ‘pottering round the garage’ or garden, but not for more public spaces. Often she would help him to dress in what she saw as suitable clothing, and then he would undress and put on his work clothes:

I’ve got sort of certain clothes which I say are okay for indoors, but not when he goes to the day centre…some days he’ll get up and he’ll... he’ll put his working clothes on and... In the summer that’s okay because he’ll do his gardening in his working clothes but usually when he gets up and puts his working clothes I know trouble’s in store!

# Within disability studies, the argument has been made for challenging the necessity to normalise appearance. Disability theorists have sought to ‘queer’ the normative body, and through doing so to validate and make politically visible the range of human experience (Samuels, 2003; Sherry, 2004). As a result, disabled people should not be required or encouraged to ‘hide’ their conditions. This aspiration becomes more complex though in the case of dementia where there is a past history of identity to reflect and respect, and where the person with dementia may not be aware of the ways in which their current expression of choice could undermine this, exposing them in ways that they would have found undignified in their earlier lives. As one family carer Mark reflected, these processes of normalisation, though they may protect the person by making their dementia less visible, can act to hide the condition socially:

... we’re all being driven to do or conform to all these too many things and, you know, people don’t know what goes on in the day-to-day if we appear to be normal. I mean we don’t want to go around with a badge, you know, *I’m la-loo* or whatever, but we do not deal with it. We do not deal with it at all.

Helping someone with dementia ‘pass’ as normal protects the individual, but leaves the wider stigma unchallenged. Mark reflects on conformity as the ‘condition of acceptance’ that normalisation imposes (Yates et al., 2008: 249). However, he recognised how failure to conform can lead to exclusion, talking about friends who ‘stopped coming’ as his Mum’s condition, and appearance, increasingly fell short of normative standards. As argued by Hughes and Patterson (1999: 608): ‘the price of integration is normalisation.’ These issues and tensions between normality, passing, and inclusion/exclusion are complex and not easily resolved, entangled with everyday dress practices in the lives of people with dementia and their families.

**Conclusion**

This chapter has explored dynamics of normalcy, ordinariness, and normalisation through an analysis of dress practice. A detailed analysis of dress as ‘situated bodily practice’ (Entwistle, 2000) can contribute to efforts to ‘reincorporate the body’ into disability studies (Linthicum, 2006). We have used dress as a lens to ‘trace patterns of embodiment as they are lived’ (Paterson and Hughes, 1999: 598, 608), and explore the negotiation of ‘corporeal and intercorporeal norms’ in everyday encounters. An analysis of dress brings into focus patterns of bodily dys-appearance in relation to physical difficulties with dressing, but also dynamics of normality, passing and stigma which fluctuate across different spatial contexts (Deegan, 2010). Dress can make visible – as well as conceal– dementia as a form of impairment, with small ‘slips’ in the maintenance of a normal appearance and dress becoming read as signs of the condition. However, dress can also support a sense of ‘feeling normal’ through the maintenance of clothing and routines which sustain biographical continuity at an embodied and tactile level.

This chapter highlights how difficulties with dress can disrupt the flow of day-to-day life, and betray efforts to maintain a ‘normal’ appearance. As has been argued in relation to the physical environment, one possible answer is adaptive design solutions. However, our research also suggests problems with adaptive clothing, which can be viewed as stigmatising or as inconsistent with the person’s embodied biography and identity. A focus on difficulties with dress and adaptive solutions can also reflect a limited, medicalised focus, which ignores the wider social contexts, relationships, and meanings within which dress is embedded (Candy, 2007). Such solutions tend to focus on the functionality of dress at the expense of any discussion of what is viewed as ‘fun’ or ‘stylish’ (Linthicum, 2006). Design solutions cannot be understood in isolation from the contexts and relationships within which they are embedded, although there is now research that is beginning to take such dynamics into account (Kabel, McBee-Black, and Dimka, 2016).

Focusing on dementia also brings these debates on normalcy, normalisation, and dress into new terrain, opening up new questions and challenges. Arguments for a ‘politics of difference’ (Coleman-Fountain, 2016), which resists the normalisation of disabled bodies, become more complex in the context of cognitive impairment such as dementia since it raises issues of choice, agency, and control. Nonetheless, a focus on dress highlights the importance of an embodied approach in thinking about dialogue between the social model of disability and dementia. Restricting discussions to dementia activism, which relies on cognitive and verbal ability, can exclude people with dementia who are less verbally fluent or visible. Instead, perhaps the best way forward is to extend a ‘carnal politics of the everyday’ to dementia (Paterson and Hughes, 1999), focusing on everyday encounters, and how agency, normalcy, and oppression are enacted and negotiated at an embodied level, recognising dress as part of this.

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1. Dementia is not generally included under the rubric of disability in popular understandings. However, the social model of disability has now been broadened to include cognitive or sensory impairment. Like other aspects of disability, the diagnosis, experience and response to dementia is shaped by socio-cultural context, and physical and social barriers shape experiences of dementia as disabling (See: Downs 2000, Kitwood 1997). [↑](#endnote-ref-1)