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Supporting Me To Be The Person I Want To Be

**Betsi Cadwaladr
University
Health Board**

**Understanding, Reflecting and Responding to Transgender
Issues in Dementia Care – *a Reflective Model for Health
Care Staff***

Foreword by Margaret Hanson

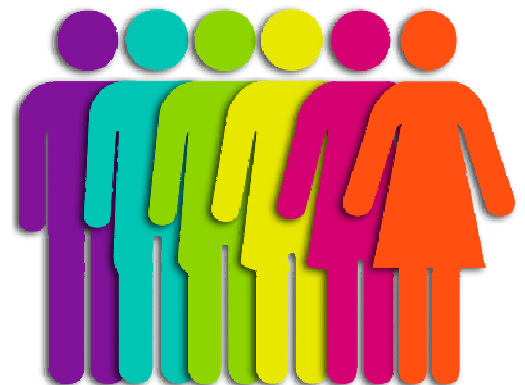
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Written in Partnership with
activists within the transgender
community of North Wales





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Foreword

I am delighted to support the publication of this set of guidelines and look forward to their implementation in practice. Their origin lies in some informal conversations a couple of years ago with representatives of the transgender community in North Wales about the needs of older transgender people with dementia. This was an issue I knew very little about at the time but I did know that it was important and I wanted to help improve the health board's service for this group. So I reached out for help to staff in the Mental Health Division, who were keen to get involved. An innovative partnership developed between these staff and representatives of the transgender community. They came together to co-create a research project; published an academic paper on their work; and had their efforts recognised by the Royal College of Psychiatrists! Not content with these achievements, they have now developed these guidelines. They are real proof of what the NHS can do when our staff listen to what those we serve truly need and I hope they will bring about real change in how the NHS in North Wales supports this unique, but vulnerable, group of older citizens.



Margaret Hanson

*Vice Chair BCUHB
& Older Person's Champion*

Our Aims Are:

'To raise awareness of transgender issues in relation to dementia care, to clearly set out as an aide memoire the protection in law for transgender people and, to offer a model for promoting effective and compassionate dementia care for transgender people'

The term 'transgender' applies to a varied section of the population and ranges from those of our fellow citizens who may describe themselves as occasional cross dressers to others who undergo gender reassignment surgery. Whilst frequently placed within a broader lesbian, gay and bisexual group, transgender is inherently distinct as it is not about sexuality or sexual preference but rather a way of describing those whose gender identity (the internal sense of ones gendered self) and its expression (the ways by which one communicates this to others) are dissonant with their gender at birth.

There are those who are drawn towards the expression of a masculine or feminine identity and some who would see themselves as non-binary, sometimes feeling masculine, sometimes feminine and sometimes genderless. The whole is commonly associated with a way of being and living that others in society fail to understand or often have any respect for.

For many it has unfortunately been an experience of discrimination, hatred and hostility and there are high levels of mental health problems, including depression and suicide, amongst transgender people. There is an expectation from within the transgender community that health service staff will show discrimination and negative attitudes towards them. This is uncomfortable to state and some will find it difficult to accept but the evidence repeatedly shows that there is an unacceptable degree of discrimination embedded within the NHS. Not surprisingly many choose not to be open about their gender identity and most research into the size of the transgender population will invariably be under reporting.

SECTION 1

Introduction

What is Transgender?

However, times change and slowly transgender people are more accepted into society. Discrimination is still too prevalent but transgender activists, such as those involved in writing this guidance, have shown the courage required to stake their claim to fairness, equality and justice in society. By doing so they have encouraged others, both transgender and non-transgender, to make a stand, to promote universal rights and for each individual to enjoy the right to be the person that individual wants to be. Whilst there is still some way to go transgender people are increasingly open and as they age we will be aware of far more transgender people affected by dementia than ever before.

Dementia, as a set of physical illnesses affecting the brain and its functioning, is a collection of common signs and symptoms which impact upon much more than just memory. Whatever the changes that dementia brings people who are affected by it are our fellow citizens and have the right to be involved in and derive the full benefits of citizenship. Without any distinction this includes transgender people who develop dementia.

There is no place for discrimination of any kind in the NHS and, like all other citizens transgender people have a right to expect that when health care is required it is compassionate, safe, effective and prudent. In meeting that expectation we are reminded of two things. Firstly as health care workers we choose to be public servants and can make no distinction about which public we serve, and secondly that dementia care is the business of every member of the NHS and all have a duty to uphold the highest of standards of service.

Our Approach

Raising Awareness

This reflective guide is not a piece of paper written to tick a box or fated to gather dust on a shelf. It has been written in partnership with activists from within the transgender community of North Wales who have challenged us to get the tone, language and content right. The approach to its development has been published elsewhere and we regard the subsequent issuing of this guide as both an important clinical tool and a form of transgender activism.

The guide aims to raise awareness of transgender issues in relation to dementia care, to clearly set out as an aide memoire the protection in law for transgender people and, to offer a model for promoting effective and compassionate dementia care for transgender people.

Community

The Transgender Lived Experience



“ I knew I needed more but was frightened to act ”

Jenny

I must have been around five when I started to realise that something was not right, I found it difficult to relate to other boys and was far more content playing with the girls, I loved helping my mother around the house, particularly cooking and sewing. On the other hand I hated having to play football and other male orientated games. Sometimes I would sneak up to my parents' bedroom and dress up in my mother's clothes. I found myself constantly being told boys don't do such things and threatened with being taken to the doctors, I found school particularly hard as I was bullied a lot due to me not wanting to associate with the other boys.

It was in the 80s that I finally realised I was not the only person that felt the way I did, and what a relief that was, my wife was still completely unaware of my secret and it was not until the early 90s that I finally plucked up the courage to tell her how I felt, I remember it so well my wife was devastated by my news and the following months were awful, eventually she came to accept me and realised that I was still the same person she loved. deep down I knew I needed more but was frightened to act, frightened of losing my wife and family, frightened of losing my job, frightened of being homeless. This state of affairs carried on until 2012 when I suffered a minor heart attack, suffering such an event made me reevaluate my live and I made the decision to transition. My wife was horrified at my decision and immediately started divorce proceedings.

All that was five years ago now, I have never felt more happy and content as I am now, my ex and I get on so well together, we are more like sisters now, I live in a wonderful community who accepted me from day one and have never questioned my identity, I am now retired but keep myself occupied as a volunteer in third sector mental health'.

Debbie

The Transgender Lived Experience

This poem is, all about me
to be the person I was meant to be
from early on I always knew
I would be a girl, when I grew!

But things are not as simple, as they seem
but this was always to be my dream
my body looked just like that of a man
but my brain always said 'You are a Mam'!

Growing up was clearly fraught with pain
Living my life, with the wrong name!
To be one of the girls was always my plan
this is not possible 'You were born a man'!

They say as you get older 'you must take a bride'
So in denial, I meekly complied
the wedding day was filed with pride
It should be me dressing as the bride!

They tell you being married, will make you a man
I just don't see, how it can!
You're now in a home full of female attire
it does nothing to quell that feminine desire!

Children came along, it was meant to be
I did not think, I had it in me!
I love them both, I am sure they know
It was not easy for me to show!

I got divorced, and married once more
but the feelings remained, that was for sure!
It came to the point, I could not deny
my life was all wrong I was living a lie!

I've changed my life, I'm now happy you see
I've even changed my name, I am now 'Debbie'!
I now live my life as it should always have been
I can honestly tell you, I am living my dream!!!!!!!



“ You were born a man! ”

The Transgender Lived Experience

Alex

I was born female at birth but when I was 4 or 5 years old I knew I was in the wrong body. I always played with boy's toys and always dressed in boys clothes.

I hated my body as it wasn't like a boy's body. I got married and had children when I was 21. At the time I just had to act normal because I didn't know who to turn to or what to do about me wanting to be a man.

My kids were too young so I left it until they were both adults to tell them. I spoke to them both and explained how I felt and that I wanted to be male, they were both great about it and supported me.

When I came out to everyone in 2014 my brother was great with it all, he calls me his big brother but my parents were disgusted in me saying 'you were born a girl not a boy' and still to this day they don't talk to me'.

“ I didn't know who to turn to ”



Cathy

The Transgender Lived Experience

'The earliest memory I have is from about the age of 7, when I recall saying my prayers at night and asking to be a girl when I woke up. Needless to say, my wish wasn't granted. I do recall at that time playing with my mother's clothes, but even then I understood that people would consider me to be odd if I ever expressed my desire, so it remained my secret.

I went to a single sex school, which did me no favours at all. I had no interest in traditionally boy's games and I was no good at sports. University followed and I was really isolated. I had no idea that there were others like me. I didn't know what support there was.

Work followed, I was living in shared accommodation, so the opportunity to be myself was still very limited and I still didn't feel able to tell anyone how I felt. I still didn't understand.

I knew I was different, but I still didn't appreciate how. By now, I had a small wardrobe, but dressing remained private and infrequent.

I moved to Manchester in 1980 and met my wife almost immediately. We clicked and married two years later. I resolved to put my gender issues to one side. I was going to be strong and make it go away, so the clothes went.



“ I knew I was different ”

The Transgender Lived Experience

During the mid-80s everything clicked into place. I started to understand exactly who I am but I was in no position to address it. My wife wasn't at all well, and whatever I do, I won't knowingly do anything to hurt her, so the secret remained.

By now the dressing was back, and, dressing frequency increased until I was caught. After quite a lot of tears we started talking and concluded that it wasn't the end of the world. I could be myself when she wasn't around, but she didn't want to know otherwise.

That worked for a year, but I needed contact with other people like me and suggested that I join a support group.

Leading a double life like this was producing too much tension though for both of us, and I went to see a counsellor. The brief was to find a way of coping without transition, but it quickly became obvious that a lifetime in and out of counselling would follow if I chose that route.

A visit to my GP and eventually I went to see a private specialist, and started the transition route.

Transition is now almost complete. I have no regrets except that I didn't do it much earlier. I can explain most of the things that were wrong with my early life. I have self-confidence. I relate more readily to people. I'm happy'.

Protection by Law

The Equality Act (2010) concerns itself with unlawful discrimination (treating some people worse than others because of a protected characteristic) and applies to all protected characteristics:

The Equality Act (2010)

The Equality Act (2010)

Applies to all protected characteristics

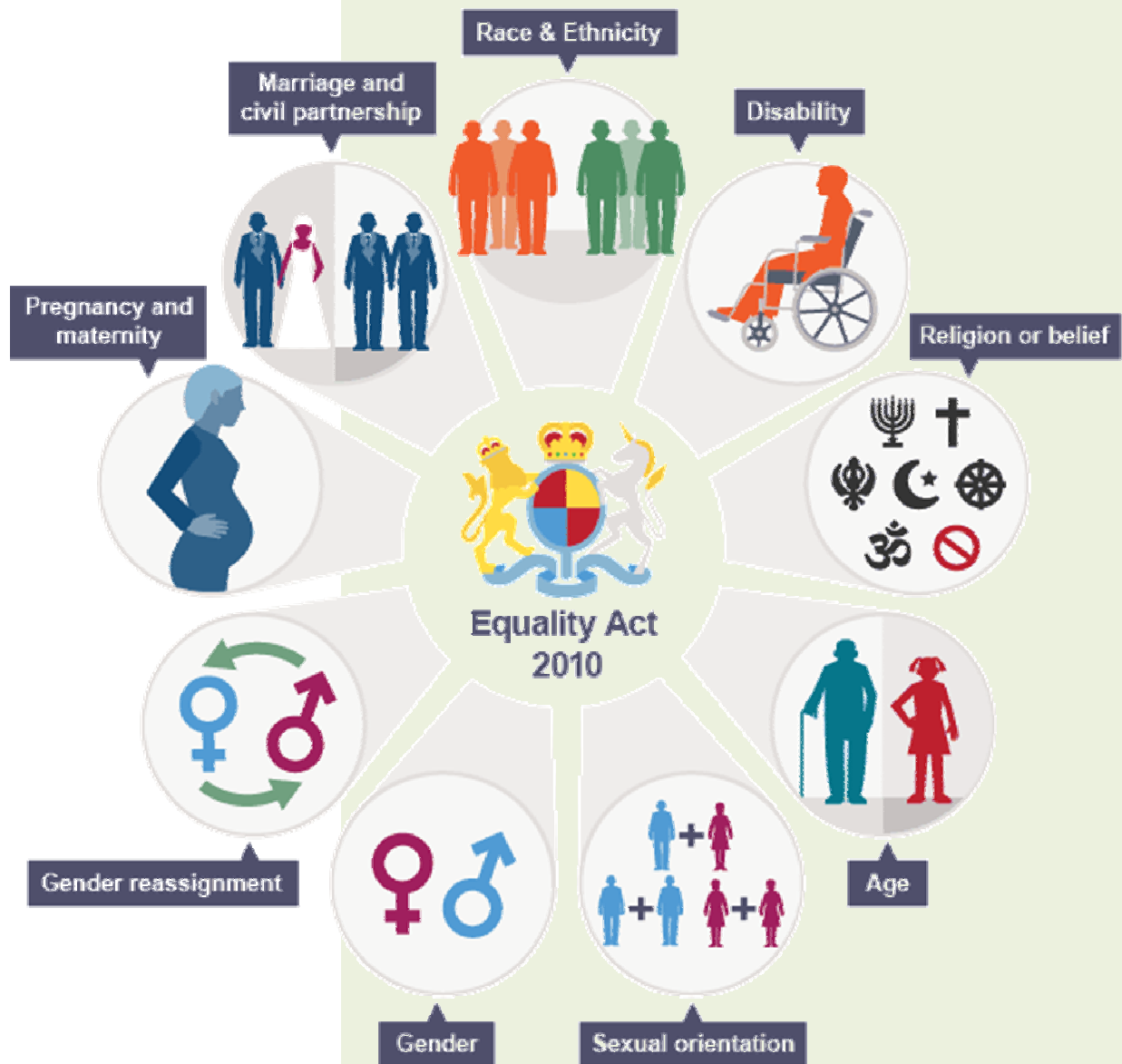
- Age
- Disability
- Gender reassignment
- Pregnancy and maternity (which includes breastfeeding)
- Race
- Religion or belief
- Gender
- Sexual orientation

Transgender specific protections include ...

A healthcare provider which is providing separate services or single-gender services must not exclude a transsexual person from the services appropriate to the gender in which the transsexual person presents (as opposed to the gender they were born with) unless they can objectively justify this.

Where a transsexual person is visually and for all practical purposes indistinguishable from someone of their preferred gender, they should normally be treated according to their acquired gender unless there are strong reasons not to do so

If the person is unconscious or incapacitated when admitted, staff should look at how that person presents. There should be no investigation as to a person's genital gender unless this is specifically necessary in order to carry out treatment



Where someone has a gender recognition certificate they should be treated in their acquired gender for all purposes and therefore should not be excluded from single-gender services.

For a transsexual person, protection from unlawful discrimination because of gender reassignment begins once they have proposed to undergo gender reassignment. To be protected, that person does not have to have a Gender Reassignment Certificate, nor do they have to have changed their name by any legal process, nor do they have to be living full-time in their preferred gender

In single-gender accommodation, even if physical differences would identify that person as a transsexual person, sufficient privacy can usually be ensured through the use of curtains or by accommodation in a single side room adjacent to a gender-appropriate ward. This also applies to toilet and washing facilities (except for communal shower facilities).

Protection by

The Equality Act (2010)



The Equality Act 2010

The Equality Act (2010)

Regards unlawful discrimination as ...

- | | |
|---|---|
| <ul style="list-style-type: none"> • Treating the person worse than someone else because of one or more protected characteristics. • Doing something to the person which has (or would have) a worse impact on that person and on other people who share a particular protected characteristic than on people who do not share that characteristic • Harassing a person who has one or more protected characteristics. | <ul style="list-style-type: none"> • Treating a person worse than someone else because that person is associated with a person who has a protected characteristic • Treating a person badly or victimising that person because they have complained about discrimination or helped someone else complain or done anything to uphold their own or someone else's equality law rights |
|---|---|

Health care providers must NOT ...

- | | |
|--|---|
| <ul style="list-style-type: none"> • Refuse to serve a protected person or refuse to take that person on as a service user, patient or client. • Stop serving or working for that person if they still serve or work for other service users, patients or clients who do not have the same protected characteristic. | <ul style="list-style-type: none"> • Give that person a service of a worse quality or in a worse way than they would usually provide. • Give that person worse terms of service than they would normally offer • Put that person at any other disadvantage |
|--|---|

Human Rights

The Human Rights Act (1998)

There are many international agreements guaranteeing basic human rights to all people, without discrimination. The **Universal Declaration on Human Rights**, which is now sixty years of age, is one of the best-known agreements of this kind. The United Kingdom has signed and ratified the Convention. Within Europe, there is the European Convention on Human Rights.

Again, the United Kingdom is a party to the European Convention on Human Rights and in the **Human Rights Act 1998** it belatedly made it part of our law, enforceable in local courts and tribunals within Wales. Local Health Boards must, other than in very exceptional circumstances, apply the European Convention. The **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006 (UK)** also promotes and protects the rights of disabled people including a person with dementia.

Taking human rights based approach is about using these international human rights standards to ensure that people's human rights are put at the very centre of policies and practice. Human rights represent all the things that are important to us as human beings, such as being able to choose how to live our life and being treated with dignity and respect. They are based on a number of core values, including:

- Fairness
- Equality
- Respect
- Dignity
- Autonomy

Health boards as a public body have a legal requirement to act in accordance with the **Human Rights Act (1998)** therefore the core **FREDA values** should be at the heart of everything we do.



Wales: Act

Social Services and Well Being (Wales) Act 2014

The **Social Services and Well-being (Wales) Act 2014**, also imposes duties on local health boards that require us to work to promote the well-being of those who need care and support, or carers who need support and authorities must have 'due regard' to the United Nations Principles for Older Persons.

The Act aims to make care and support personal to individual needs and will change how social services and health boards operate across the whole of Wales.

Assessments are carried out in the best way to meet an individual's needs, the focus is on what matters to the person and how they can use their own strengths and resources to do those things.

For the first time, the Act also ensures that carers are treated on the same basis as those using services and have a right to support



In England, this is covered under the obligations set out in the **Care Act 2014**, and the **Social Care (Self-directed Support) (Scotland) Act 2013** in Scotland.

The Model

Love-Centred based on *Kitwood*

Tom Kitwood wrote about the psychological needs of people with dementia. It would be appropriate to suggest that these are the universal psychological needs for all human beings. To achieve truly person centred care we must be ready to engage with the person and those who are significant to him or her to discover how these needs can be met.



The central need of 'Love' is different to the other needs. 'Love' is an unconditional acceptance of the other person, an expectation that we provide what the person needs in a truly accepting way with no expectation of reward. The other needs: 'Attachment', 'Comfort', 'Identity', 'Occupation' and 'Inclusion' will be different in every single person you meet. Maintaining these needs is integral to maintaining the personhood of the individual with dementia.

The Model *continued*

Personhood is literally who we are as individual people but as dementia progresses the person may find it more difficult to express their own personhood.

At a time when a person, perhaps because of dementia, learning disability, delirium or stroke, cannot tell us who he or she is as a unique individual then we as healthcare workers have a moral obligation and professional duty do that for them.

If we do this well then we have safeguarded and upheld the psychological needs of that person so their personhood can be maintained. If we do it badly then we let slip away the essence of who that person is an care environments were personhood is not upheld and psychological needs ignored there is a much greater risk of distress, apathy and what is often labelled 'challenging behaviour'.

For a transgender person who has dementia the practice of supporting personhood remains the primary goal of the healthcare worker but there are other specific considerations that should be made when considering Kitwood's model of psychological need. We set these out as we ask you to reflect upon and apply the model in your clinical practice.

Model in Action

Applying the Model

Humans are social beings. We need to feel that we are connected to other people who we can trust. This need may be particularly apparent during times of distress or when we are feeling upset. When people are asked to consider what or who they are attached to in their life, common considerations may be their family and friends. Often people feel attached to their own home, a pet or an object, such as a prized toy or a physical reminder of their past. This need is attacked when the person's attachment is invalidated or they are blamed for something they have or have not been able to do.

Attachment

All people with dementia have their attachment needs threatened when entering a care environment. Each person is then no longer in the home that he or she feels attached to or do not have regular contact with the people they feel close to.

Families, friends, even pets, should be welcomed into care environments to support the person's attachment need. Talking to the person and their family regarding their attachments will help you understand how you can help to maintain this need.

For a transgender person with dementia there may be further considerations for health care staff before they can meet the person's need for attachment.

“

My parents were disgusted in me saying '*you were born a girl not a boy*' and still to this day they don't talk to me”

1 Attachment

The relationship between the person and their family may have changed since they voiced their need to transition. Families who have been unsupportive of the person's desired gender may wish to promote the person's previous gender identity if the person is no longer able to maintain it themselves. In these circumstances, friends who have been supportive of the person's gender identity may not be recognised as the person's next of kin.

The unsupportive family may then provide healthcare workers with information that is detrimental to the person's current gender identity.

As dementia progresses the person often finds past memories more comforting. This may result in the transgender person no longer recognising more recent friends who have been supportive yet they may accept older acquaintances who have previously opposed their gender transition.

Attachments with family and friends may also be threatened when a transgender person lives or knows a person with dementia.

The person with dementia may recall the person's previous gender and become angry or laugh at the person. Without malice, the person with dementia may publicly voice a friend or relative's desire for transition when the individual has not publicly voiced this themselves.

Exercise One



Exercise One

A family tell Care Staff that they must dress the transgender person with dementia in clothes inappropriate to their current preferred gender identity

1. What actions should you take?
2. What does the Law say you should do?
3. How could this dilemma have been avoided?

2 Comfort

2 Comfort

We all have the need to feel close to others. Relationships that provide us with warmth and tenderness also enhance our sense of security. The need of comfort may be provided through physical means which could include the simple action of giving someone a hug. Soothing words of comfort may also provide someone with the reassurance that they are somewhere that they can relax and feel safe. Certain personal objects or routines may also be a great source of comfort for some people.

For a person with dementia who may be in an unfamiliar care environment there is an immediate need to prioritise their comfort. This can be achieved by health care staff who offer the person warmth throughout their interactions whilst using comforting words and actions to alleviate their anxieties.

Comfort is often attacked when staff feel that they have a task to complete and therefore make the person with dementia feel frightened that there will be negative consequences for them if they don't do as they are told (e.g. a healthcare worker tells a patient that his wife will be angry with him if he doesn't have a shave every morning). This need is also undermined when healthcare workers refuse to give the person with dementia the attention they are asking for or when information is given at a rate too fast for the person to understand.

To ensure that the physical comfort needs of a transgender person with dementia are upheld there are some

2 Comfort

Continued health screenings will need to be considered based on the person's current and previous gender identity. Medical staff must take account of the person's previous gender when assessing the results of blood tests as anomalies may be disregarded as normal if only the person's current gender is considered.

The formal change of gender identity includes the provision of a new NHS number. Therefore, healthcare workers should be mindful that current medical case notes may not offer a comprehensive physical history of the person. Cross gender hormone treatment must continue throughout the person's life. There is a high risk of considerable physical ill being for the person if this medication is stopped or forgotten.

Whilst the previous considerations may be life threatening if ignored by health workers the following points must also be considered to uphold the psychological comfort of the person:

- The person must feel comfortable within their own appearance. The person with dementia may not be able to maintain their desired appearance themselves and should therefore be assisted to do so in a relaxed manner.
- Be aware that the person is likely to feel uncomfortable if addressed by the incorrect pronoun. This is likely to affect the comfort of any transgender person but further consideration should be given for the person with dementia who may be having difficulty maintaining their current identity.

2 Comfort

- Comfort can be provided by the physical environment and you should consider your care environment and what could make the person feel uncomfortable (e.g. being asked to use the incorrect toilet for their current psychological gender identity).
- Many transgender people have not undergone surgery and express identity through their style of dress. They may feel uncomfortable if a physical examination “outs” their biological sex. This is one reason why some people do not present for health checks.

Exercise Two



Exercise Two

In a dining area one group of ladies and a group of gentlemen are eating lunch. A transgender lady is told by a health worker that she must sit with the men as the ladies would prefer that

1. What actions should you take?
2. What does the Law say you should do?
3. How could this dilemma have been avoided?

3 Identity

Each of us has the need for personal identity. From the clothes we wear and how we choose to wear them, to our preference of the food we eat or prefer not to.

These are all ways that help us and others identify who we are. It is what makes us unique but also can be the reason we are part of a group and it can be our identity that enriches our contributions as a member of a group.

Maintaining a person's identity can relieve anxiety at times of distress and improve the dignity and respect experienced by an individual. It can create a sense of worth and meaning and often prevent distress by acknowledging the person as who they are.

Our identity can be threatened by a simple admission to any care environment, where our identity could be reduced to a list of medicalised characteristics and behaviours and, our self, left at the main entrance. This is regardless of being a person with dementia, but the risk of this happening can be increased if you are.

Meeting an individual's need for identity can be achieved in numerous ways that are all made easier by getting to know the individual. Addressing the person by the name they wish to be called.

People in any care settings have a wealth of knowledge, experience and expertise in a wide range of areas. By knowing this health care staff can refer to these attributes

3 Identity

“

From the age of 7, I recall saying my prayers at night and asking to be a girl when I woke

”

3 Identity

and also learn from them creating a sense of value and comfort. Being aware of personal perspectives can also assist in avoiding creating distress unnecessarily through actions known not to be the person's preference.

Tips for maintaining an individual's identity:

- Treat people as individuals and try to see the world from the perspective of the individual
- Challenge stereotypes whilst supporting the individual to maintain contact with family and friends
- Make time to speak with the individual and their family and friends to broaden your knowledge of the person

For a transgender person with dementia there may be further considerations for health care staff when attempting to meet the person's need for identity

It is not only the name but the pronoun (masculine – he, him, Mr or feminine – she, her, Miss, Mrs) that must be considered when healthcare staff address the individual. There may be anxieties and concerns that the person may not recall what they have previously disclosed during appointments with regards to gender and their journey.

A person may not recall their current gender. They may see themselves as being pre-transition resulting in heightened disorientation and anxiety. They may be surprised to see the physical changes that have occurred.

“
What if I forget
who I have
become and
think I am who
I used to be? ”

3 Identity

A person may not understand why they are being referred to as their preferred gender when they believe that they have not publicly voiced this preference.

A person who has never voiced a different gender preference may now begin to do so.

A focus of transitioning is the retention of identity whilst changing gender. Likewise, the focus of those who care for people with dementia should be to support the individual to maintain their identity in the face of declining cognitive and functional abilities.

There could also be implications if a person with dementia no longer recalled that a close relative who openly expressed their transgender identity with concerns voiced that a mother with dementia living with a cross dressing son may ask 'who is that woman?'

As the person with dementia begins to find it difficult to uphold their own identity, those who may have kept their desire for transition secret may find themselves expressing these desires openly which could cause great emotional distress for the person and their family.

A concern for transgender people is that after death they may be buried as the wrong gender or name. It would be of benefit for those who gender themselves differently from their birth gender but have not completed gender reassignment surgery that they discuss and have their preferred gender recorded with the GP. Without an application the person may not be recognised under the gender recognition act 2004, increasing the likelihood that the preferred gender will not be supported in the event they are unable to do this themselves.

“

Very soon the biggest and most exciting part of my journey is to happen, gender realignment surgery, this is a monumental part of my journey and in a way the beginning of a new chapter in my life. The surgery itself will not make me any more or less of a woman that I already am

”

3 Identity

Another practical step would be to encourage the individual to create an advanced directive and appoint a lasting power of attorney for health and welfare.

This would then state preferences with regards to death and dying along with having someone who would be able to voice them on the individual's behalf should they no longer have the ability to do this themselves.

Further information on advance directives and lasting power of attorney can be found on **NHS Choices** website and also by contacting **Age UK**.



“ I want to die who I am now, not who I was and be remembered as such ”

Exercise Three



Exercise Three

A transgender person with moderate dementia has just been admitted to your care. They approach you and start a conversation

1. What should you do now to support the person's need for identity?
2. Who could you involve to support you?
3. What will you do with the information you have obtained?

4. Occupation

4 Occupation

This relates to more than just a job. It is about the sense of having something meaningful to do and it is about people with dementia continuing to live lives of purpose and fulfilment. Occupation and activity are essential for health and wellbeing and are part of being a human. This need rarely diminishes with age or cognitive decline. If done correctly occupation and activity can support the meeting of an individual's need for inclusion and identity.

Occupation has the potential to promote strengths, enhance relationships and improve self-esteem. Therefore, meeting this need can meet many of the other needs identified in this section.

The focus of occupation should be around healthcare staff having a can do attitude and identifying with the person what their strengths and abilities are as well as what they want to do. It is important to note that level of engagement in occupation is likely to fluctuate throughout the day and that it is realistic for individuals to become fatigued and this should be respected and activity adjusted accordingly to meet the change.

The need for occupation is at risk in people with dementia as there is often a "can't do" attitude by those around them and inappropriate activities that lack purpose are provided. This can lead to feelings of failure. A "Can't do" attitude is developed by focusing on the person's deficits not abilities. The continuation of "can't do" inevitably results in not doing. This can result in boredom for the individual.

4. Occupation

Boredom is a contributing factor to feelings of frustration but be mindful that also being tasked with something meaningless can also create this response.

For a transgender person with dementia health care staff need to consider the following when providing occupation and activity

Health care staff may overly focus on gender specific activities as we attempt to let the person know we accept their chosen gender identity. However, this can come across as patronising and as a failure to understand the individual person.

Gathering a personal history and identifying areas of interest the individual has and using this to inform activity choices would have better outcomes than purely identifying an activity based on gender.

The chosen activity may misrepresent the individual's gender identity but may also create a feeling of wellbeing, meaning and value. It is therefore always worthwhile asking the person what they would want to do and not being surprised by the response.

Reminiscence therapy is a commonly used activity for people with dementia. There are inherent risks that may occur using reminiscence that could lead to distress or unwanted disclosure.

Health care staff must try to understand what the person would want to be disclosed.

Exercise Four



Exercise Four

At times it may be necessary to adapt an activity such as the need to be mindful of what an individual would want disclosed during group reminiscence

1. Describe an activity and how you would adapt it to meet the needs of a transgender person with dementia
2. How would you know your adaptations had worked?
3. How would you ensure other staff follow your adaptations?

5 Inclusion

5 Inclusion

We all want to feel that we belong, that we are respected and sufficiently valued so that we can engage and connect with those around us. Even though inclusion is a universal human right aimed at embracing all people, irrespective of race, gender, disability or other attribute which can be perceived as different it is not a right that is universally enjoyed by everyone.

It is reported that many people with dementia and their carers feel marginalised not only by society but also by their own friends and family members.

For transgender people the experience is one of almost daily institutionalised marginalisation and informal exclusion. Institutionalised because in our society transgender people are highlighted as being at odds with what is regarded as 'normal' and this is particularly evident in respect of engagement with religion, politics, community affairs, health or social care and employment.

Informal exclusion is related to stigma and the overt identification by others of the difference of the person. This is often obvious such as through the violence and aggression allied to a hate crime but usually it is more subtle, the deliberate use of an incorrect gender pronoun, snide remarks, distancing by others or becoming the subject of gossip. At its core social exclusion denies some people access to the many aspects of life that most people take for granted. Included amongst those aspects are such things as employment opportunities and financial security; good

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40 percent of
people with
dementia report
being avoided
by others”

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health; positive and supportive family and social relationships and a safe place to live. Neither people with dementia nor transgender people can take such things for granted. The nature of institutionalised and informal exclusion sees transgender people as subject to high unemployment and financial insecurity, to not accessing routine health care screening, to suffering the breakdown of family relationships, to victimisation, harassment and violence from neighbours.

Both transgender people and people with dementia say that they just want to be treated like other people and with the focus placed on their strengths and not on their impairments or on what makes them different. Raising awareness of the ways in which social exclusion occurs can lead to overcoming some of the issues which in turn will help improve the quality of life for transgender people with dementia and for those who support them.

Some of the concerns raised by older transgender people when they consider also living with a diagnosis of dementia are set out below.

- There is a fear that already socially excluded lives will become even more so and they will become progressively more powerless to prevent this happening.
- There is a fear of approaching services that have been shown to be as potentially discriminatory or mocking as some parts of society. This includes a fear of not being provided with the correct facilities, being gendered incorrectly and of publicly being on the receiving end of discriminatory language.

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Transgender people are the most targeted minority group for violence and aggression ”

- There is a fear that dementia may lead to the transgender person using the incorrect gender terms about themselves in public and inadvertently revealing a secret that they have tried to keep.
- There is a fear that the social exclusion associated with dementia may also exclude people who move between genders from opportunities to express both their masculinity and femininity.
- There is a fear that whilst social isolation is an unenviable way of life it does offer some people a safe place to hide away. Admission to hospital brings people into social environments with little privacy and as other patients are a microcosm of society, gossip and ridicule may follow.
- There is a fear of the use of segregated living spaces not only creates social exclusion but fuels stigma and suggests there is something different, unnatural, unsafe about the transgender person.

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There was no one to turn to and being absolutely terrified I attempted suicide at the age of 15 ”

Exercise Five



Exercise Five

A transgender person with a moderately severe dementia is admitted to an acute hospital ward. You have a free bed in the male bay, another in the female bay and a free side room. The person's gender identity is female and clearly expressed as such, however, her gender at birth was male and occasionally she becomes disoriented and refers to herself as 'Barry'

1. In which of your free beds do you nurse this person?
2. Why?
3. What does the Law say about the rights this person has which must be protected?

Final Thoughts

Regardless of gender identity, preference or expression our title states what sits at the very heart of dementia care.

As that persons illness strips away their sense of self and self-identity we are reminded just how vulnerable our personhood is.

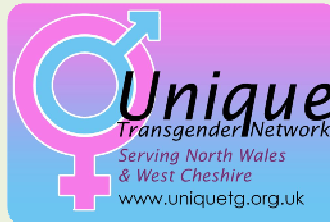
If we are unable to promote these things for ourselves then we are risk of being assigned a different self-identity by others than we would otherwise wish for.

It is the greatest fear that people newly diagnosed with dementia have and for transgender people affected by dementia it is made worse by the potential loss of a preferred gender identity, denial of gender expression or an imposition of a gender identity that others think is more socially acceptable.

The greatest act any health care worker can perform to achieve excellence in dementia care is to uphold that fragile and crumbling sense of self. It is a human and selfless act that is in the gift of every single one of us.

Support Me To Be
The Person I Want
To Be

Useful Links



Unique Transgender Network – a voluntary group supporting transgender people in North Wales and West Cheshire.

www.uniqueg.org.uk

@unique_tg



Sparkle – the National Transgender Charity

Sparkle Charity
83 Ducie Street
Manchester
M1 2JQ

www.sparkle.org.uk

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