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How to Provide Excellent Care Services to our LGB or T clients with Dementia?

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1. What is Lesbian, Gay, Bisexual or Transgender?

'Lesbian' is a term used to describe female homosexuality, it signifies a woman who is sexually attracted by other women. Many lesbian women also use the term "gay woman" to describe themselves, as an alternative to lesbian.

'Gay' or 'Homosexual' is a term used to describe men sexually attracted to other men.

'Bisexual' is a term used to describe people who are sexually attracted to both men and women.

'Gender identity' is the internal sense of one's gendered self (e.g. as a woman, man, girl, boy, androgynous) and 'gender expression' is how a person's gender identity is communicated to others, through behaviour, clothing, hairstyle, voice, and emphasising, de-emphasising or changing physical characteristics.

'Transgender' refers to a diverse and inclusive community of people ranging from part time cross dressers to transsexual people who undergo gender reassignment surgery. It is an umbrella term for people whose gender identity and/or gender expression are those not traditionally associated with their birth sex.

'Gender dysphoria', also known as 'gender identity disorder', is a medical term for anxiety, confusion or discomfort about birth gender.

A 'transsexual' is a man or woman who has a lifelong feeling of being trapped in the wrong body. The sense of belonging to the opposite sex is so strong, they feel that the only way to achieve peace is to change their body to match their mind. Some people seek counselling or therapy to help them to cope with their confusion or discomfort and others go through the process of living in their chosen gender role, with the help of hormones. Others undergo 'gender reassignment surgery'. A person who is transitioning from female to male (FtM) can be known as a 'trans man', while a male to female (MtF) transsexual person can be known as a 'trans woman'.

A 'transvestite' is a man or woman who dresses and acts as the opposite gender either occasionally, regularly, in private or in public. Some people live full time as the opposite sex.

Transgender people often experience inequality as a result of being both a minority and a less than understood group.

Transgender people like to be addressed as the gender they refer to themselves as (for example if someone who to you looks rather masculine but is dressed in women's clothes and behaves like a woman and calls herself Mary, instead of referring to Mary as "him" or "this man" you should refer to them as "her" or "this lady/woman").

2. Clients' Sexual Orientation or transgender history – it's none of our business, or is it?

There is a common assumption in society at large that everyone around us is straight (i.e. if they are a man they will be attracted to women and if they are a woman they will be attracted to men), yet statistics show that 1 in 15 people in our society are either lesbian, gay or bisexual and 1 in 100 is transgender. The Equality in the East Report (2010) estimated the male transgender population over the age of 15 in Suffolk to be 2892.

This means that at some point or another, whether you know it or not, you will have come across either clients or staff who will be lesbian, gay, bisexual or transgender (LGB or T). Sexuality and gender identity are an intrinsic part of everyone's identity, LGBT or straight, it's just that LGB&T are more aware of this as they have had to deal with being viewed as "different" in society. A person's sexual orientation or transgender history is an intrinsic and important part of who they are, it is part of them as a human being. Therefore, if you do not really know your patients, how can you ensure you are addressing their needs and delivering appropriate services to them?

You **could even be in breach of equality legislation** if you do not know your clients' sexual orientation and discriminate against them as a result of this.

For example: An old woman moves into your care home and her female partner tries to explain to you "their situation". You say "our patients' sexual orientation is a private matter and none of our business" so you don't learn about their civil partnership. One day the patient's sister comes into your care home and says she does not want you to allow this "partner" of her sister to visit her and you stop all visiting rights for your patient's partner. As a civil partner, she has as much right to visit her loved one as a husband would have to visit his wife, but by stopping her from visiting her partner (due to blood relatives asking you this) you could be discriminating against her and her partner on the grounds of civil partnership and/or sexual orientation (Equality Act 2010).

We suggest you try and record the sexual orientation and transgender status as part of your assessments of clients. Even if some clients may not want to answer the question, it is up to the service provider to show they are open and do not discriminate against any people no matter their protected characteristic. Below in the handout you will see guidance on sexual orientation and transgender monitoring questions.

3. How to monitor sexual orientation or transgender identity?

At the beginning of your monitoring form you should always include a statement outlining why you are asking this information, who will have access to it and strong reference to confidentiality.

At the beginning of your current monitoring form you can add the following wording: "At (organisation name) we aim to ensure that our services are accessible to all members of Suffolk's population. Therefore we would like to ask you for some equal

opportunities information. By giving us this information, you will help us to evidence who we are reaching and who we are not, so we can continually make improvements to ensure our services address our clients' needs."

	"H	ow would you define your sexual orientation?"		
		I am a Gay Man/Homosexual I am a Gay Woman / Lesbian		
ls <u>y</u>	you	r gender identity* different to your birth gender?		
0	Υe			
0	No Pr	refer not to say		
	Do			
	✓	Wait until the end of the conversation before proceeding to ask the equal opportunities monitoring questions. Make it clear that this is a separate process, which will not affect the outcome of your discussion.		
	✓	Explain why this information is being asked for – we can only improve our system and address any gaps if we know who is accessing it and any particular issues they may have.		
	✓	Remember that asking a person for this information is asking a personal question. So the way in which you ask the question is very important. Be sensitive in the language you use.		
	✓	Tell the customer that they do not have to disclose the information if they don't want to. They are likely to feel less intimidated when given a choice.		
	✓	Assure the customer of the confidentiality of what they are telling you, and refer to legislation if appropriate, such as the Data Protection Act 1998.		
	✓	Note any approaches you find more successful, and feedback to your		

manager and team – it might help others.

Do not

- x Do not try to guess a person's diversity categories. You may think you can tell what the sexual orientation or gender a person is, but you may not be correct. The customer, will either tell you or they will choose not to. If they do not disclose, then record 'prefer not to disclose'. Your responsibility is to ask the question.
- x Do not push someone into disclosing information. It is their choice, and they do not have to tell you.
- x Do not probe them for further information or how it affects them. Only record their disclosure.
- x Decide which categories you are going to ask questions about depending on how comfortable you feel. If you are unsure about how to ask the questions, seek additional guidance and training.

NB: Not all non-heterosexual people (especially those of an older generation) choose to identify as "lesbian", "gay" or "bisexual" – they may prefer not to label themselves or to use other words. They may refer to their life partner as their "friend" or "companion" rather than my "boyfriend/girlfriend" or "partner". When conducting an interview with the client, take your cue from the person as to the kind of language you should use. Follow the language used by the client.

4. My client is LGB or T – what's so different about their situation?

a) They don't feel safe – because they always have to "come out" over and over again to new people and are scared of their reactions – imagine you are straight and every time you meet someone, or go to the doctor, they keep asking you about your gay or lesbian partner or talk in a way that constantly assumes you have a partner which is of the same sex as you. If you are confident enough about your relationships and the way you are, you will say "I am straight, I am not gay/a lesbian" fully knowing that by doing this may sometimes mean you are looked at in a strange way or the conversation becomes awkward... or you will be rejected! This is what some LGB or T people feel all the time: Constant pressure and fear of rejection about who they **really** are. **Constant assumptions** about their life, their partner and their way of being. Also dementia clients are more likely to be older and have lived through a time when being lesbian, gay, bisexual or transgender has been less acceptable in British society than it is now and they will have concerns about "coming out" to staff and even their carer. Up until the Sexual Offences Act 1967 it was illegal for two men to have sexual relations and most of your

older clients will have lived through a significant period of their lives where having a relationship with another man was illegal. Until the Equality Act (Sexual Orientation) Regulations 2007 made provision for regulations to address discrimination in the provision of goods and services on the grounds of sexual orientation, most of your clients were used to being discriminated against in the provision of goods and services on the basis of being gay, bisexual or a lesbian without having any legal ability to challenge this.

SOLUTIONS:

When you discuss with clients, give them subtle messages to show that you are open to people of any sexual orientation or transgender identity. For example you can do this by saying that you are a service provider which values diversity and is very inclusive towards your clients, no matter their gender identity, sexual orientation, race, disability or creed. If you feel one of your clients may be in a gay or lesbian relationship (their "friend" who is the main carer is also of the same sex for example and they seem very close) but they feel unsafe to come out, show them you are open to talk about the relationship by saying things like: "clearly you care a lot about him/her", "How long have you lived together?".

A lesbian client said: "It was such a relief when the manager of the extra care scheme where I was living encouraged me to open up about my lesbian identity. She didn't push me but she gave plenty of positive messages that she didn't have a problem. It immediately helped me to feel that I was accepted for the whole of me, and more important that I felt safe in my own home."

Have images and language in your communications (brochure, leaflets, website, notice board, etc) which show inclusivity towards same sex couples and transgender people – most images and language of services providers refer only to straight couples and only photos of straight couples are usually displayed either in their brochure, leaflet or website. Demonstrate how inclusive you really are by putting also photos of same sex couples in your marketing and communications material. Instead of just using words such as "husband" or "wife" also consider using gender neutral words such as "partner". You don't have to give up the words "husband" or "wife", you can just say "your husband, wife or life partner".

Ensure that staff are aware that LGB&T family carers can feel particularly isolated and may have had experiences of hate crime and / or discrimination from service providers by delivering training to staff to enable them to respond appropriately when an older person does come out.

What exactly should staff know?

First and foremost it is about culturally competent care and understanding the differences in people. For example: It could be small things like **making sure their language is appropriate** (see above regarding "wife, husband or partner"), **not ignoring the information provided by the client, asking them about their life** and **taking this into account** when devising the **personalised care plan**. However there could be other issues such as the client's family not knowing about their lesbian, gay, bisexual or even transgender status and **ensuring confidentiality**

(not "outing" the client to the family by mistake) or they may want their partner to visit but they may not want other staff to know that this person is their partner.

b. Staff who are LGB or T may not be "out" because work colleagues do not truly practice non-discrimination and this will affect your LGB or T clients feeling unsafe and isolated.

Your clients need to feel they are part of the "family" especially in a residential care setting. When professional care staff within the organisation are scared about coming out and consider clients' "coming out" "their problem" not "our problem" makes LGB or T clients feel unsafe and isolated.

SOLUTIONS:

If staff "came out" as well it would help the clients feel more open and relaxed about their sexual orientation or transgender status. Provide more education on the meaning of being non-discriminatory for all staff and have a zero tolerance policy for discrimination, victimisation or harassment of both staff and clients due to their protected characteristic, including sexual orientation or transgender status.

Arrange **staff awareness and training on LGB&T issues**. We suggest you do this in small groups where staff will feel safe to ask questions as well as express their experiences or views. Care and support staff should not discuss their views about LGB&T people or issues in front of clients.

c. Sometimes services providers don't acknowledge them as the "next of kin" which can cause distress – Take for example Martin: his gay partner John is in a home and he has a medical problem and was admitted into hospital. From the moment John was moved into the residential care home, Martin told them he is John's partner. When he telephones the home to check how John is doing, he is told he isn't there and he's been in hospital for the last 3 days. No one informed Martin as they would have informed a wife about her husband. As the cared for person deteriorates or dies, the full impact of this on their partner is not acknowledged and, therefore, support is not offered. Service providers do not often see that the same sex partners also suffer bereavement. It can be more difficult if the partner has not told them they are partners and have described themselves as a "friend" or "neighbour" and as such the depth of their relationship will not be known.

SOLUTION:

Same sex partners feel the same pain and suffering when their loved one is in hospital or in a care home like any other husband or wife would. When a new resident moves into the home or you start providing care services to a new client, monitoring their sexual orientation and finding out their relationship with the person they quote as their next of kin is crucial to ensuring any unnecessary distress or suffering is caused to your client's same sex partner.

Training on sexual orientation and transgender clients will help to ensure that your staff are aware of this.

d. Legal issues: unless a lesbian or gay partnership is registered (a civil partnership), there is little legal protection for gay and lesbian people. For example: the term 'next of kin' has a very limited legal meaning, and it is associated to the disposal of property to blood relatives when someone dies without making a Will. When LGB couples are not out, the carer is less likely to be involved in planning and decisions around their partner's care. Issues such as next of kin or who has power of attorney cannot be openly discussed. Older LGB couples will often have chosen not to have undertaken a Civil Partnership and therefore are not protected in the law in the same way and all health and care-related staff need to be aware of this. Where the cared for person lacks capacity to make decisions, it is important staff have a good understanding of the issues that might affect LGB&T people.

SOLUTION:

The Mental Health Act 2007 gives equal recognition to same sex partners, but only when they are in a registered civil partnership. Another way of solving this issue for **LGBT clients** is **to have a Will.**

Alert the partner or the carer of your LGBT clients to the importance of both partners having made a proper Will to ensure that it is clear who inherits their house/property and other belongings. This will be especially important if members of the family of the person with dementia are hostile to the couple and could possibly contest the Will. Encourage the person to set up a lasting power of attorney (LPA) as soon as possible. This legal document allows the person the client has chosen as the attorney to make decisions on the client's behalf about their personal welfare. The LPA gives authority to the partner or the person they trust to make decisions on their behalf when they do not have the mental faculties to make decisions for themselves.

e. They are more likely than the general population to be the clients of care services and less likely to have support networks around them and are isolated. Carers of LGB or T people may not be the traditional family carers of straight people and are often ex-partners. For example: many transgender people as they are transitioning (changing their sex from male to female or vice-versa) later in life can "bring about massive loss in terms of family, friends and support networks" therefore they have to rely on friends and contacts they have made probably when they were transitioning. Also, 40% of gay men over 55 years are single compared with 15% of heterosexual men – this also means that it is very likely they have no or a partner children to look after them.

SOLUTION:

With LGB or T there is a need to look to groups for support and advocacy organisations. It is important to recognise and remember that **lesbian**, **gay**, **bisexual or transgender clients may not have the support structures in place as other heterosexual clients and may need to be signposted to support groups**. Contact the Suffolk LGBT Network (contact details on the cover of this guide) and speak to them about such support networks.

f. They are more likely to come across prejudice and have their personal lives discussed and commented on by care staff.

Moreover, there will always be a conflict between religion and sexual orientation. Sometimes older people or staff may have strong religious beliefs which they feel justifies their lack of acceptance of LGB&T people.

For example: Mary is an older lesbian woman and she changed care agencies three times before finding one that she felt safe with, although not safe enough to be out to them. Comments and questions made by her previous care workers led her to believe that they were indulging in local gossip and speculation about her sexuality.

Research into LGBT with dementia has identified that LGB or T people who had themselves worked, or are working in the health and social care sector, expressed the most concern about service providers and staff awareness of diversity. Moreover, some care staff are migrant workers from countries where the discrimination and harassment of LGB&T people is still very accepted and even legal. These sorts of concerns and issues would influence LGBT clients' decision to disclose their sexual orientation or transgender status. Some of them may even feel safe to come out to a care home manager but not to care staff. LGB and T people disclosed during research that they were "fed up of hiding their sexuality" and would like to live somewhere where they could "be me".

SOLUTIONS:

Ensure at first stages of the recruitment process there are really rigorous and meaningful equality and diversity questions. To show you are truly inclusive you can add a statement when you advertise the vacancies that that you are open to LGBT clients. This is very likely also to deter people with prejudice and homophobia from applying for the jobs. Under the Equality Act it is the service provider's responsibility to make their organisation trust worthy. Make sure your organisation looks and is a place where LGBT people feel safe to be in.

Just like with disability or race equality, there are some steps you can take to ensure LGBT people have equal access to your services and having marketing material with language and photos of same sex couples is a way of making your services open to LGBT clients. LGBT people should have the choice to disclose or not. They are more likely to disclose their sexual orientation if they feel safe and protected by your organisation.

We suggest you also deliver LGB&T training to staff and link equality and diversity to their performance review.

g. LGB or T avoid routine health care checks due to past negative experiences which may affect how illnesses are diagnosed, so their dementia is likely to be identified later than other straight patients'.

SOLUTION:

The more affirmative health and care services become, the more confident they will be to access routine services. **Have images and language in your communications** (brochure, leaflets, website, notice board, etc) **which show inclusivity towards same sex couples and transgender people** – most images

and language of services providers refer only to straight couples and only photos of straight couples are usually displayed either in their brochure, leaflet or website. Instead of just using words such as "husband" or "wife" also consider using gender neutral words such as "partner". You don't have to give up the words "husband" or "wife", you can just say "your husband, wife or life partner".

Ensure that staff are aware that LGB&T family carers can feel particularly isolated and may have had experiences of hate crime and / or discrimination from service providers by delivering training to staff to enable them to respond appropriately when an older person does come out.

What exactly should staff know?

First and foremost it is about culturally competent care and understanding the differences in people. For example: It could be small things like **making sure their language is appropriate** (see above regarding "wife, husband or partner"), **not ignoring the information provided by the client**, **asking them about their life** and **taking this into account** when devising the **personalised care plan**. However there could be other issues such as the client's family not knowing about their lesbian, gay, bisexual or even transgender status and **ensuring confidentiality** (not "outing" the client to the family by mistake) or they may want their partner to visit but **they may not want other staff to know that this person is their partner**.

h. They may not feel confident to tell you their needs and suffer in silence – for example: Roger is a gay man and visits his partner Jim in the care home. When he goes to see Jim, he is always sitting in the living area with other residents. This makes it more awkward for Roger to have personal contact and relationship with Jim. He doesn't feel confident enough to ask you to move Jim to his own room so they could have some privacy. The reason this happens could also be because of ageist assumptions that older people are no longer sexual beings.

SOLUTION:

When you take on a new client, try to find out about their life experience, their likes and dislikes, hobbies, interests, friendships and relationship. Devise for them a care plan that takes into account any patient how he or she is, as an individual with specific needs and differences. Make sure the care plan includes social contacts and interests as well as specific needs due to their sexual orientation or transgender identity.

i. I) They may have difficulties with the kind of service or support offered as it does not address their needs and they don't necessarily fit in and feel welcome – for example: a lesbian woman whose partner has Alzheimer's and is in a care home attends a carers' group. She feels very much as she is the "odd one out" as the other carers appear to all be "married and very heterosexual". The moment she will start talking about her female partner, it will clearly show she is a lesbian (even if she does not say it out right) and she and her partner

will have a different family structure, perhaps they are no longer in touch with their families due to rejection when they started their relationship, they may not have any children or other support groups other than friends and other lesbian women.

II) Another example of difficulties with the service or support provided are Memory Groups: If you are running a group session where clients talk about memories from their youth this may be difficult for a gay or lesbian, or transgender person. The people they talk about, the memories that are important to them, their interests and humour will have been affected by their experience as a lesbian or gay person, but they may feel unable to express this as these are not likely to be similar to the experiences, memories, interests and humour of the other straight people in the group.

This can also happen in Reminiscence Groups – for example: Mark was not included in reminiscence groups, as he seldom seemed to have anything to contribute – even when he had tried to talk about his past life, other residents seemed very uncomfortable with his references to same sex relationships and experiences. It just seemed easier all round not to mention Mark's past life.

Bisexual clients for example may be that they are in a heterosexual relationship but start talking about previous same sex relationships, or vice-versa.

SOLUTIONS:

It might be particularly important for the person to have contact with other gay/lesbian/transgender people to support their identity and confidence at a time of loss and change. See if there are other residents in the home or other clients in the Memory Group who are also lesbian/gay/bisexual or transgender and if they could be part of the same group.

They **might prefer a gay care worker** if the choice was available.

Speak to other care services providers in your area or with Suffolk Family Carers and **ask if they have or are in touch with other carers who are lesbian, gay, bisexual or transgender**. You could help put them all in touch and help form or add members to an existing LGB&T carers support group. **Kelly Weston at Suffolk LGBT Network has set up an LGB&T carers support group.**

You could also try and **include equality and diversity as a regular statement part of the carer support groups** you are involved with to show any potential LGB or T carers that they would be welcome, however **could you guarantee that the statement can be supported by open views of the other members of the group?** Carers of people who are in care homes are of an older generation where prejudice and oppressive attitudes towards LGB or T people were the norm, an LGB or T carer may find themselves attacked in such a meeting for being open about his/her same sex relationship. This is why perhaps a LGB or T specific support group would be more appropriate.

j. A transgender man or a woman may also have fear of rejection – even if at a first glance he or she may appear a man or a woman, when it comes to more intimate interactions with others, including being cleaned or changed by someone else, many transgender people (who have had the sex change operation or not) feel scared of staff's reaction to their genitalia, either because of the operation and they may not feel it looks like a natural male or female genitalia, or because of the expectation of staff – if they appear very female but have not had the operation female staff may have a negative reaction to them. For Transgender people the main purpose of transitioning was just to get on and live their life in the gender they had always felt they were. They usually would only disclose being transgender if in need of personal care.

SOLUTIONS

Provide training to care staff about transgender people, the various differences between the people who are considered transgender (transsexual, transvestite, cross-dressers, intersex) and also **about the health care needs of post-operation transsexual people**.

Have inclusive leaflets which show that you understand and consider transgender clients' perspectives within your service provision.

Ensure that you understand the provisions of the Gender Recognition Act 2004, the Equality Act 2010 and the Civil Partnership Act 2005 and demonstrate this understanding in your equality and diversity statements and in consent forms. Specifically, understand how legislation relates to religious and cultural views of homosexuality. Staff should be trained and supported in challenging other staff and clients' prejudiced views and attitudes. Older LGB&T people themselves may not be aware of the requirements of the Equality Duty on service providers, so this information should be made available to all staff and clients.

You might find it helpful to understand that the support trans people need is more similar to what people who are experiencing illness need i.e. when they're in the midst of the transitioning process, which is in part a medical one, they need a lot of support but once they have transitioned and if it is successful, they just want to get on with their lives in their new identity. They don't want their trans history to dominate their care and they want to be seen and identified as the gender they have transitioned TO, not the gender they have transitioned FROM or be identified as "transgender".

k. A transgender person fears service providers won't understand the situation gender recognition certificate – transgender people have concerns about service providers' knowledge and understanding around the complex issues surrounding Gender Recognition Certificates and marriage. For example if a married man goes through gender reassignment treatment to become a woman, she is eligible to apply for a Gender Recognition Certificate. He then must divorce his wife and if they want to continue their relationship under similar conditions as marriage, they'd have to go through a civil partnership.

SOLUTION

It is illegal to pass on information about trans status (without consent) if not linked to medical care. Provide training to care staff about transgender people, the various differences between the people who are considered transgender (transsexual, transvestite, intersex, etc) and also about the legal implications of Gender Recognition Certificates. Have inclusive leaflets which show that you

understand and consider transgender clients' perspectives within your service provision.

Fear of "being outed" by partner when they get dementia - if you are in a gay or lesbian relationship but like to keep this as private as possible (due to fear of prejudice or harassment from neighbours from example), when your partner gets dementia they start to behave differently and sometimes become very outspoken. They could "out" you (about being gay or a lesbian) to neighbours or other people in your lives or on the street and cause additional distress and potentially invite harassment and bullying from neighbours or passersby. Also, this could happen in case one or both partners are in a care home. For example: If Chris (who is the gay partner of Kevin) moved in the care home you work in and you would know Kevin only as "the friend", Chris could "out" Kevin to you and to all the other staff and residents which could cause Kevin distress or it could make him fear the staff's attitude or quality of care would change towards Chris due to his sexual orientation. Transgender people also fear that if their partner develops dementia, he or she could inadvertently "out" them as a transgender person to care providers which might create problems for their partner, but also put their partner at risk of

transphobia by association (i.e. being ridiculed, harassed or treated

SOLUTION

Create a safe and open environment for all your clients and ensure their confidentiality is being kept at all times. Have a zero tolerance for abuse or harassment of clients, their partners and staff. When you discuss with clients, **give them subtle messages to show that you are open** to people of any sexual orientation or transgender identity. For example you can do this by saying that you are a service provider which values diversity and is very inclusive towards your clients, no matter their gender identity, sexual orientation, race, disability or creed. If you feel one of your clients may be in a gay or lesbian relationship (their "friend" who is the main carer is also of the same sex for example and they seem very close) but they feel unsafe to come out, show them you are open to talk about the relationship by saying things like: "clearly you care a lot about him/her", "How long have you lived together?".

badly/differently because they are the partner of someone who is transgender).

Have images and language in your communications (brochure, leaflets, website, notice board, etc) which show inclusivity towards same sex couples and transgender people – most images and language of services providers refer only to straight couples and only photos of straight couples are usually displayed either in their brochure, leaflet or website. Demonstrate how inclusive you really are by putting also photos of same sex couples in your marketing and communications material. Instead of just using words such as "husband" or "wife" also consider using gender neutral words such as "partner". You don't have to give up the words "husband" or "wife", you can just say "your husband, wife or life partner".

Resources:

- Suffolk LGBT Network Information and Monitoring Toolkit
- A review of Equalities Evidence in the East of England (2010)
- Stonewall www.stonewall.org.uk
- Alzheimer's Society support for LGBT people
 http://alzheimers.org.uk/site/scripts/documents_info.php?document
 ID=1100
- Opening Doors Report Lois Peachey Age UK