

Information for LGB&T people and their friends, partners and families



- There are more than 800,000 people in the UK with dementia
- 1 in 3 people over the age of 65 will develop dementia
- The number of people with dementia will double in the next 40 years
- Older LGB&T people are statistically more likely to live on their own
- Older LGB&T people often worry about 'coming out' to service providers so they can find it difficult to access services

Government estimates give the number of lesbian, gay and bisexual people as between 5% and 7% of the general population. For Trans people an estimate of 1% would appear to be an over-cautious figure. One study suggests the number of Trans people in the UK could be around 65,000 (Johnson, 2001, p. 7), while another estimates around 300,000 (GIRES, 2008)

### **Getting older and dementia**

Many of us notice that our memory becomes less reliable as we get older. Tiredness, stress, overwork, anxiety, depression, some physical illnesses or the side-effects of certain medications can all affect our memory. And, of course, some of us have always been more absent-minded than others!

## The symptoms of dementia

Dementia is not a single illness but a group of symptoms caused by damage to the brain. The symptoms include loss of memory, mood changes and confusion.

Dementia affects everyone in different ways, but you should seek help without delay if your memory is not as good as it used to be and especially if you:

- **struggle to remember** recent events, although you can easily recall things that happened in the past
- forget names of friends or everyday objects
- · have problems thinking and reasoning
- notice changes in your personality, for example, getting very cross with people you love, when you didn't used to
- feel anxious, depressed or angry about your forgetfulness
- feel confused, even when in a familiar environment







#### For the Individual



- An early diagnosis can help in three ways: whilst medication isn't appropriate for everyone, if prescribed it can slow down the progress of dementia, a diagnosis gives you time to get your affairs in order and the opportunity to access support and information
- A good diet and moderate exercise, as well as taking medication, can help slow down the effects of dementia
- Learn how to adapt and continue with all your normal daily activities as long as you can - use post-its, mobile phones, calendars etc. to remind yourself about appointments, medication, important dates and social activities
- **Work out a routine**. Put important things like keys and mobile phones in the same place
- Let trusted friends, family and neighbours know as well as offering practical support (keeping a spare set of keys) they can be a good source of emotional support
- **Don't give up** a dementia diagnosis doesn't mean the end. You can still live well with dementia
- **Plan ahead.** Write a living will and decide on your end of life care. Choosing someone to act as your Power of Attorney for your health and welfare, or property and financial affairs is important, so do it while you can. If you don't, then a court will decide who makes those decisions for you
- Find ways of recording your past the way you want to remember it, and enlist people to help you

## For partners, friends and family

- Speak clearly where possible in a quiet environment.
  Keep calm and slow down
- Body language: people may sometimes find it hard to follow what you are saying, but making eye contact and smiling makes a huge difference

- Listen carefully and give plenty of encouragement, as well as looking out for other clues about what they want to communicate
- Show respect and patience don't rush the person. It can be a huge effort to communicate so give the person time
- **Different reality**: sometimes people with dementia are confused and can say things that don't make sense to you. Avoid embarrassing them by contradicting and try to find a way round the situation.
- Offer help and support but also remember that people value their independence, so don't try to take over
- Don't take things personally. There may be personality changes which are part of the illness. Try not to get distressed if your partner gets confused about past relationships, often memories from the past are stronger than present ones
- Don't negate feelings: LGB&T people with dementia may re-experience difficult times in their coming out or Trans journey. Remember, time may have passed, and laws changed, but these memories can have a huge emotional impact

# When it all feels like its getting too much, support yourself



- It can be a long grieving process as the person you love changes over time. Keep loving them but don't feel guilty if you feel frustrated...you are only human too!
- Connect with others in a similar situation. Consider attending a support group for partners, family and/or carers of those with dementia
- **If things are getting on top of you** talk to your GP or any organisation mentioned in this leaflet

## For community groups

- Be accepting of memory failings: as everyone gets older we can experience age related conditions that can cause distress
- Accompany someone to the group, offering transport if possible or appropriate. This may be an informal buddy or a carer from a professional service
- **Respect the individual's privacy:** be guided by them and support them, but remember it's up to them to disclose their dementia or LGB&T identity to others
- **Find out what needs the person has** and make changes to accommodate them. Help the person retain their sense of identity, independence and self worth
- Help them to feel secure by creating a relaxed environment where they are treated with respect, courtesy and are given encouragement. Revisit any ground rules that you have for your group and don't be scared to add 'dementia friendly' guidance
- Involve the person in appropriate activities by offering sensitive support and reassurance; you may need to give reminders
- Include the person in conversation. Allow them to say things at their own pace and in their own way. Find time to listen to them and show that you have an interest in their opinion
- Everyone likes to have a joke, but sometimes illchosen words or terms can hurt. Jibes about memory loss and forgetfulness should be challenged and people should be mindful of the effect that language can have.



## **Organisations which can help**

#### The Equity Partnership

Plays an active role in supporting LGB&T communities in Bradford. We produce a free electronic news bulletin and organise a bi-monthly network for groups and individuals. Equity Partnership also organises one-off events on issues relevant to LGB&T communities. The Equity Centre offers a relaxed meeting space, a fully-equipped training resource and a venue for events. right in the centre of Bradford. The Centre is an ideal place for groups, meetings and training events. We provide training for agencies on I GB&T issues. The Centre is also available for hire - contact us for details.

01274 727759 admin@equitypartnership.org.uk

#### The Labrys Trust

We are a group of older lesbians in West Yorkshire meeting regularly to identify and improve services to meet our needs as we grow older. We have a confidential information and signposting telephone-line service every Wednesday from 7pm to 9pm:

07907 469927 labrys.trust@ymail.com www.thelabrystrust.com

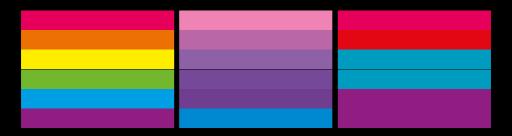
#### The Alzheimer's Society

If you are worried about your memory or need information and support, please contact us: Bradford Office: 01274 586008 bradford@alzheimers.org.uk For more information about dementia and LGB&T specific fact sheets ring the Alzheimer's Society Helpline (Monday – Friday 9am - 5pm; Saturday & Sunday 10am -4pm) or visit the website: www.alzheimers.org.uk National Helpline: 0300 222 1122

#### Yorkshire Mesmac

Works with gay and bisexual men and men who have sex with men. and the wider LGBT communities to offer support, information and resources. All sites across Yorkshire offer condoms and lubricant. counselling, outreach services, training, groups, testing and one to one support.

For more information please visit www.mesmac.co.uk.



Organisations mentioned in this leaflet are supportive of LGB&T people, those living with dementia and those affected by it. You have the right to a fair and equal service.

This leaflet was supported & funded by:













