

Not 'just' a friend

best practice guidance on
health care for lesbian, gay and bisexual service
users and their families

Royal College of Nursing & UNISON

This guidance has been produced by the Royal College of Nursing and UNISON, the public services union.

The **Royal College of Nursing** (RCN) is the voice of nursing across the UK and is the largest professional union of nursing staff in the world. The RCN promotes the interest of nurses and patients on a wide range of issues and helps shape healthcare policy by working closely with the UK Government and other national and international institutions, trade unions, professional bodies and voluntary organisations. To join the RCN please call RCN Direct (24 hours) on 0845 772 6100 or visit our website at www.rcn.org.uk

UNISON is the trade union for public sector workers. We recruit, organise and represent workers across the health service. Our members include nursing, ambulance, professional, clerical, administrative, ancillary and managerial workers, working full or part-time. Over two thirds of our members are women. We campaign for world class public services, accessible to all. Our lesbian and gay group is integral to the union and organises nationally and locally. To join UNISON or find out more about our work in healthcare and for lesbian, gay and bisexual equality phone 0845 355 0845 (voice) or 0800 0 967 968 (minicom) or visit www.unison.org.uk

The guidance is endorsed by:

College of Occupational Therapists 106-114 Borough High Street London SE1 1LB www.cot.org.uk

Chartered Society of Physiotherapy 14 Bedford Row London WC1R 4ED www.csp.org.uk

Royal College of Midwives 15 Mansfield Street London W1G 9NH www.rcm.org.uk

Society of Radiographers 207 Providence Square Mill Street London SE1 2EW www.sor.org

Not 'just' a friend: best practice guidance on health care for lesbian, gay and bisexual service users and their families.

For the best health outcomes, health care workers and service users need a relationship of trust. Good communication and confidence are essential. The NHS Plan commits to a principle of equal access to and equity of treatment in health care services. The experience of many lesbian, gay and bisexual service users currently falls far short of this.

Research in recent years shows that most lesbian, gay and bisexual people do not have the necessary confidence to be open about their sexuality, even when it may be relevant to their health care. They fear hostile and judgmental reactions. Indeed, they may actually experience hostile and judgmental reactions if they do come out. Also, health care workers sometimes fail to recognise same sex partners and their families, isolating service users from the support and involvement in their care that can make all the difference.

But there has been a steady build up of good practice in some areas. This guidance from UNISON and the RCN, which has been endorsed by the Chartered Society of Physiotherapy, College of Occupational Therapists, Royal College of Midwives and Society of Radiographers, provides information to health care workers on how health services can give confidence to lesbian, gay and bisexual service users.

It is not about giving special treatment – it is part of the growing recognition in the NHS of the need to respond to changes in society, including family structures, and apply an understanding of cultural diversity when delivering health care.

Many of the principles in this guidance also apply to best practice in the care of transgender service users, but the issues are not all the same. Details of where to get advice on transgender issues are included at the end.

Check list for Health workers:

- Be aware that you have lesbian, gay and bisexual service users, even if you don't know who they are.
- Be sensitive about the way you request information from service users, using language which is inclusive and gender neutral.
- Ask service users who information should be given to and who should be involved in treatment decisions, explaining what this means, rather than using the term 'next of kin'.
- Ask who should be contacted in case of emergency – do not assume this will be the same person.
- Also ask the names of other people who the service user wishes or does not wish to have contact with.

- Ensure all paperwork – such as information leaflets and admission and consent forms - uses language which is inclusive of lesbian, gay and bisexual families.
- Challenge prejudiced attitudes and behaviour in co-workers, other service users and service users.
- Make it safe for same sex partners and family members to be open about their relationships if they want to, so they can be supported during illness or crisis.
- Respect privacy and confidentiality.
- If necessary, provide lesbian, gay and bisexual service users and their families with details of where to get further, specialist support, advice and information.

This leaflet can only give a brief overview of best practice in delivery of healthcare to lesbian, gay and bisexual service users. Training for all staff and monitoring of outcomes will be essential elements of any action plan on achieving good practice.

'As a registered nurse or midwife, you must respect the patient or client as an individual – you are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.'

Nursing & Midwifery Council Code of Professional Conduct

'Respect for the patient as an individual is central to all aspects of the physiotherapeutic relationship and is demonstrated at all times.'

The Chartered Society of Physiotherapy Core Standards

Next of kin

Many people in same sex relationships are concerned about the refusal of health care workers to acknowledge their partner, denying them visiting rights and access to information. In the vast majority of cases, there is no legal basis for this. It certainly hinders best health care. Your role as a health care professional is to act in the best interests of the service user. You can only do this if you have an accurate understanding of their wishes. There is common misunderstanding about the term 'next-of-kin'. In healthcare, it has very limited legal meaning and relates to the disposal of property to blood relations, when someone dies without having made a will. But the term is widely used in a number of different ways - many service users think it means someone whose relationship to them has legal recognition. So asking for a person's 'next of kin' may confuse them and is unlikely to give you the information you actually need.

Living wills, health care proxies, power of attorney, registered partners

People who want their partner to be involved in decisions about their care and treatment may take a number of steps. They may make a living will and appoint their partner as a health care proxy. They may grant their partner 'enduring power of attorney' over their financial affairs, should they become incapacitated. They may register their same sex partnership with their local authority, if it provides such a scheme. They may plan to register their partnership under the proposed civil partnership scheme for same sex couples, which will give rights akin to marriage to registered partners.

However none of these steps (or indeed marriage) give a person the right to make treatment decisions on behalf of their partner. Equally importantly, the right for a partner to be involved in treatment decisions is not restricted to those partners who have such evidence of commitment.

'No- one can give consent on behalf of an incompetent adult. However, you may still treat such a patient if the treatment would be in their best interests. 'Best interests' go wider than best medical interests, to include factors such as the wishes and beliefs of the patient when competent, their current wishes, their general well-being and their spiritual and religious welfare. People close to the patient may be able to give you information on some of these factors. Where the patient has never been competent, relatives, carers and friends may be best placed to advise on the patient's needs and preferences.'

Department of Health Guidance on Consent – www.doh.gov.uk/consent

Collette – an older lesbian - was admitted to a Neurological Rehabilitation Unit with dysphasia following a head injury, which left her with severe speech problems. Initially, her long term partner – not sure of the attitudes of staff – hid their relationship and concealed her detailed knowledge of Collette's life. Once she was assured that she was not going to have to deal with homophobia on top of the distress over the illness of her partner, she was able to become fully involved in Collette's care and care decisions. This improved the situation beyond measure for all involved, for Collette, for her partner and for the professional staff caring for Collette.

Confidentiality and Documentation

When asking about partners or family members, healthcare workers need to tell service users the reason for the request and how the details will be recorded. They should also explain how service users can gain access to their notes. Not all lesbians and gay men feel comfortable using the terms "lesbian" or "gay" to define themselves and some will have concerns about such information being documented. Healthcare workers should

never make a record of a service user's sexual orientation without their prior permission. If you seek such permission, you should discuss with the service user what the information will be used for, who will have access to it and how confidentiality is maintained.

'Occupational therapists shall at all times recognise, respect and uphold the autonomy of clients and their role in the therapeutic process including the need for client choice and the benefits of working in partnership. Occupational therapists shall promote the dignity, privacy and safety of all clients with whom they come into contact.'

The College of Occupational Therapists Code of Ethics and Professional Conduct

Good practice in seeking information on contacts

Health care workers should only seek information on contacts which is relevant to a service user's health care. In the vast majority of cases this will be limited to:

- who the service user wants to have around;
- who they wish information to be given to, whether in person or over the phone;
- who they might wish information to be withheld from, whether in person or over the phone;
- who should be contacted in case of an emergency;
- who they wish to be involved in decision-making, should they become incapacitated.

A service user should – if they choose - be able to give information about their chosen contacts without having to declare their sexual orientation. They should also – if they choose – be able to identify a same sex partner, and have their partner acknowledged.

'It is not always necessary to know the details of each client's personal and sexual situation. It is, however, important that each client feels comfortable enough to share with her midwife information on aspects of her personal life that may affect, or be affected by, pregnancy and birth. Midwives should carefully review the information they routinely collect from clients, and assess whether the way they ask for it is both specific enough to gain the facts they require, and sensitive enough to avoid making implied assumptions or value judgements. For example, why might a midwife ask about her client's relationship with the baby's father? She may need to know about the home and social support available to her client, or who the birth partner will be, or about the baby's paternal medical history. All these questions can be asked specifically, without implying assumptions about the client's sexual choices.'

Other family members

Like all people, lesbian, gay and bisexual people have not just partners but families who they may care for and who may care for them – be they parents, children, siblings or whoever. Some of these relationships have legal recognition, such as a lesbian co-parent who has applied through the courts for parental responsibility. Others do not, such as the 'in-law' of a gay partner. What matters is the caring relationship, not the legal status of the relationship. Health care workers must respect this without intrusive and unnecessary questioning.

Not all lesbian, gay and bisexual people are in relationships – single people should have the same respect for their chosen contact person, whoever this may be.

What to do when there is conflict with other relatives

Some lesbian, gay and bisexual people may have difficult relationships with their blood relatives because of the refusal of these relatives to accept their sexuality. It is the service user's wishes that must be taken in to account.

The situation is more complex if the service user is unable to state their views – because, for example, they are unconscious or unable to fully weigh up treatment decisions. Healthcare workers should not make judgements themselves. If there is a disagreement between relatives and a friend or partner of the service user, a compromise should be sought. All healthcare workers will be used to dealing with situations like this – apply the same good practice to lesbian, gay and bisexual service users as in other situations of family conflict. At all times, it is the best interests of the service user that are paramount.

Mental Health Services

In mental health services the issue of next of kin is often confused with the role of the nearest relative (defined under the Mental Health Act 1983). The nearest relative has the role of advocating on behalf of a service user. In the past, it has been difficult for same sex partners to gain recognition as the nearest relative. However, recently a lesbian has been successful in gaining recognition for her partner as nearest relative under the Human Rights Act (i.e. where someone lives with another person as husband or wife for 6 months).

Where a service user is not looked after under the Mental Health Act (the majority of service users receiving help from mental health services in the NHS) the same considerations apply as elsewhere in the NHS. There is no need to limit who may be contacted to either nearest relative or 'next of

kin'. It should be determined by the service user's choice and could be their partner or a friend.

The Adults with Incapacity (Scotland) Act 2000, expressly recognises a same sex partner as nearest relative. Changes proposed to the Mental Health Act for England and Wales would also give same sex partners the same rights as heterosexual partners to be involved in decision making. Whatever changes to legislation are finally agreed, best practice is to involve those closest to the service user and with best knowledge of the service user's own wishes.

Sam – a gay man whose partner had Alzheimer's – made the decision to be open about their relationship to the staff of the home his partner was in. Although Sam had power of attorney [legal authority to make financial decisions for his partner], he had difficulty getting recognition as the most appropriate person to make decisions about his partner's affairs, with health workers and other professionals continually querying who he was.

Working with people with learning disabilities

For services for adults who have a learning disability, sexuality can be a complex issue. People with learning difficulties may not understand their feelings, especially if they are different from those expected by society, and they often have little access to information. This puts a particular responsibility on workers who provide support. It is vital that this is done proactively, not only as a response when things go wrong.

Dealing with Death

Health care workers should recognise that when a same-sex partner has been bereaved they may not receive the same support and recognition as a heterosexual partner. Information on specialist services - available from local lesbian and gay switchboards – should be offered to them.

The Human Tissue Act (1961) allows a non relative to receive a body, arrange a funeral and give permission for a post mortem to be carried out.

If a person dies in hospital, the hospital authority has lawful possession of the body. The hospital administrator has legal authority to determine that organ or tissue transplantation take place, as long as reasonable enquiries have been made as to any objections from either the person who has died or their surviving relatives. It is possible that a lesbian or gay partner could authorise transplantation and that the hospital administrator would also take the views of blood relatives.

Where it's working well

Within Nottinghamshire Healthcare, Rampton Hospital has sought to address the needs of lesbian, gay and bisexual service users by setting up a Rainbow Club. This has been effective in encouraging lesbian and gay service users to feel safe enough to come out within the special hospital environment and has also provided an opportunity for staff to consider the needs of lesbian, gay and bisexual service users including issues relating to same sex relationships. This is an example of dealing with social exclusion on the basis of sexual orientation by actively providing support and raising the profile and visibility of the concerns of lesbian, gay and bisexual service users.

In Brighton and Hove, a survey by lesbian and gay community groups found that nearly half the town's lesbians and gay men were not out to their GPs. This often prevented them from seeking advice and treatment. If they did seek treatment, the GP's understanding of their health needs was often limited by assumptions about their (hetero)sexuality. Armed with this evidence, the local lesbian and gay community worked in partnership with the health authority in the setting up of 'The Lesbian and Gay Friendly GP Practice Scheme', where all practice staff receive training in the range of issues around working for lesbian and gay service users.

In Liverpool, a drop -in service has been developed for adults with a learning difficulty who identify as lesbian, gay or bisexual. It is a safe place where people can talk with others in order to understand their feelings, share difficulties and successes and make their own informed decision about how to identify themselves. The service was developed by two community nurses and a generic health service for gay men. It aims to offer continual support for individuals; provide support that can be accessed easily by individuals; and develop a service that providers of care can use as a resource.

The Navajo Lesbian and Gay Health Strategy for Preston, Blackpool, Fylde and Wyre currently has 50 local organisations signed up to its lesbian and gay friendly assurance charter mark scheme. This includes NHS health care services including Accident and Emergency, GUM Clinics, GPs, young people's sexual health services as well as other statutory and voluntary services. The charter mark ensures equity of access to services and equality of employment and includes access to training, resources, support, funding and policy making for all organisations involved.

Other sources of information:

Department of Health - www.dh.gov.uk

Lesbian and Gay Bereavement Project – 0207 403 5969

Lesbian and Gay Switchboard – www.llgs.org.uk and www.queery.org.uk

Lesbian and gay carers network, Alzheimer's Society –
www.alzheimers.org.uk/Gay_Carers

Navajo Project – www.navajo.org.uk

Nursing and Midwifery Council – www.nmc.uk.org

Press for Change (transgender rights group) – www.pfc.org.uk

Organisations are welcome to copy, distribute and quote from this guidance – we want it to have the widest circulation possible. Please include reference to UNISON and the RCN as authors of the guidance.