

Social support

Key

- R** A **right** you have as a user of a service
- E** An **expectation** you should have as a user of a service, based on best practice and professional standards
- A** This is **advice** on how to get the most out of your services

Outside of my clinic, what support can I get to help me live with HIV?

Depending on your needs, a range of social support may be available, including welfare benefits, housing and social care services. There are many types of welfare benefits available including some specifically for people with long-term health conditions such as HIV. To find out if you may be eligible for any of these, visit www.gov.uk <http://www.gov.uk/> or talk to a specialist HIV support service*. You can also find out about help with housing this way. There are [local HIV support organisations](http://www.lifewithhiv.org.uk/organisations) <http://www.lifewithhiv.org.uk/organisations> around the country, and you can also get information from national organisations including:

- **NAT** - www.lifewithhiv.org.uk
- **Terrence Higgins Trust** - THT Direct on 0808 802 1221 and **MyHIV** [information standard logo] www.myHIV.org.uk
- **NAM** [information standard logo]- <http://www.aidsmap.com/e-atlas>
- **Positively UK** - <http://positivelyuk.org/>

Who provides social care?

Your local authority (council) pays for social care in your area **R**. But not all providers of social care are social workers or work for the local authority. Some community and voluntary organisations (charities) are paid to provide social support to people living with HIV.

You can find local HIV services by asking at your HIV clinic or searching online:

- <http://www.lifewithhiv.org.uk/organisations>
- <http://www.aidsmap.com/e-atlas>
- <http://www.myhiv.org.uk/>

Or call THT Direct on 0808 802 1221 (10am-8pm Monday to Friday, free to call from all UK landlines and most mobiles).

This resource was proposed by an advisory board, attended by an expert panel of voluntary sector/patient organisations. The writing of the resource was undertaken by NAT (National AIDS Trust). Merck Sharp & Dohme Limited (MSD) funded and attended the advisory board, and had the opportunity to check the resource for accuracy and balance. Final editorial control was held by NAT, taking account of input from the advisory board members and other experts.

How do I get support?

Some services provided by local HIV organisations are 'open access' or 'universal' services, which means that anyone with HIV can approach the organisation directly and ask to use them (see 'Who Provides Social Care?'). ¹ **R** The organisation may be funded to provide services to anyone living with HIV in your local area

If you need more intensive help – for example, if you are disabled and need help at home – you will have to ask your local authority for a 'community care assessment'.¹ **R**

The community care assessment is also sometimes called a FACS assessment. FACS stands for Fair Access to Care Services. This is the same assessment that will be used for everyone in England, no matter what their care need is.

[1] FACS 2010

What happens during a community care assessment?

FACS (Fair Access to Care Services) is the tool used to make community care assessments. The local authority worker using FACS will look at someone's needs and decide how great an impact these have on their ability to do day-to-day activities. At the end of the assessment they will decide if this impact is either 'critical', 'substantial', 'moderate' or 'low'.¹ **R** Because funding for social care is limited, the local authority uses this rating system to decide who will get specialist help, prioritising those with the greatest need. Different local authorities have different rules. For example, some will only give support to those with a 'substantial' or 'critical' need. Others might be able to help people with 'moderate' needs.

These are the questions the local authority worker will think about during the assessment¹:

- Is there a need which is potentially life-threatening if not met?
- Are there significant health problems?
- How easy is it for the person to do the things they want to do and feel in control of their daily life?
- Has there been abuse or neglect?
- Can the person carry out daily personal care (e.g. bathing) and domestic routines (e.g. food preparation)?
- Are there barriers to work or education?
- How are social support networks and relationships affected?
- Is the person still able to carry out their usual family and social roles (e.g. being a parent)?

If someone's life or health is seriously threatened they will always be assessed as having 'substantial needs'. But in general there are no types of needs that are more important than others. For example, the substantial problems someone is having with their relationship (e.g. domestic abuse) are just as important as the substantial problems someone else is having with showering in the morning. The person doing the assessment should ask about what you want from your life and what help you think you need to achieve that.¹ **R**

[1] FACS 2010

What about carers or family members of someone living with HIV?

People living with HIV may need to be cared for at times in their life, or may be carers of family or partners. There is support available for people who care for ill, disabled or elderly family members, partners and friends. Sometimes this support is given as part of the overall social care provided to the person who is being cared for.

However, carers may also ask for a separate carers' assessment of their own needs, if they are providing care on a regular basis.¹ **R**

Carers may apply for help with the practical aspects of caring - for example, home adaptations or transport costs. They can also apply for support so that they are able to keep working, studying or participating in other activities alongside their caring responsibilities. **E** This might mean, for example, having someone come in to help with the housework.

For more help and advice for carers: www.carersuk.org

[1] FACS 2010

What are personal budgets? Is this the same as direct payment?


Personal budgets are one way of funding the social care and support people get. The council decides how much funding you will get and then you can choose how to spend it from a range of options. For example, if you need someone to help you in your home, you can choose which care provider comes in to do this. **A** You might also spend it on aids and adjustments to your home. **A** It might help with getting around, for example, transport to a peer support group. **A** The key is that you will not have to use the services provided by the council – it's up to you.


Not all personal budgets will be direct payments into a bank account. You can have your funding held by the local authority or a chosen service provider, who will spend it for you when you have chosen the services you want. You can also have your budget managed for you by a family member, friend or carer.

Some local areas may not yet have full personal budget systems in place. But even here, you are still entitled to ask for direct payments to pay for your care and support.¹ **R**

[1] *Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009* (SI 2009/1887)

What are my rights when applying for support services?


You have the right to ask for your social care needs to be assessed through a community care assessment. As assessment must be given to anyone who “appears to be in need of community care services”.¹ 

As well as people who already live in the area, the local authority should be prepared to assess people who might soon need help.¹  This could include people who are going to be discharged from hospital or who have firm plans to move into the area in the near future, and who would need support as soon as they got there.


If you disagree with the finding of your community care assessment, you can appeal it. You can question the findings with the assessor and ask for a review through your local authority’s usual procedures.

[1] FACS 2010

Am I guaranteed social care as someone living with HIV?

Although each local authority gets funding from the Government to help people living with HIV, this does not mean that everyone with HIV will be found eligible for services in their area. But even if you do not meet the threshold for social care in your area, the local authority should still signpost you to services that might be able to help – for example, a local HIV organisation or support group.¹ 

The FACS assessment is designed to prioritise access to social care based on how limited someone’s independence is likely to be, and not their specific health condition/s, age or other circumstances.

However, even if they prioritise social care for those with the greatest needs, local authorities must also make sure that there are services to help people with less severe needs to stay healthy and independent.¹  In some areas, local HIV organisations are funded to provide these services to people living with HIV.


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[1] FACS 2010

What if my local authority isn't offering the sort of support needed by people living with HIV?

If your area isn't offering the sort of support you need, you can contact your local councillor or suggest that your HIV support organisation talk to local councillors.  You can also approach your local Healthwatch. Local Healthwatch organisations are a way for local people to have their say on health and social care in their community and to have these views shared with decision-makers. (For more information see 'Shape Your Services').

What is social care and how can it help me?

Social care is about helping people live independent, healthy and fulfilling lives. As with health care, social care services are as varied as the needs of the people accessing them.

The sort of support some people living with HIV might need includes:

- Support with coming to terms with an HIV diagnosis and disclosing this to family and friends
- Information and advice to help with problems with housing, welfare benefits, financial issues, immigration and accessing NHS services
- Advice on dealing with discrimination and stigma
- Help in your home (e.g. cooking, cleaning, shopping, bathing).

Social care services available to people living with HIV include:

- Peer support groups, where people living with HIV can meet together to listen to and support each other
- Contact with an HIV specialist social worker
- Practical advice and advocacy from an HIV support organisation.
- A support worker or carer to help you in your home and/or when you are out and about.

Not all people living with HIV will need or be able to get all of these types of help. It will depend on your needs and how much HIV is affecting your ability to manage daily life.

This is not an exhaustive list and depending on your needs there might be other ways social care can help you and your family.