

Health & Wellbeing

If you are living with HIV, it's very important to take care of your immune system to ensure your health and wellbeing.

In addition to taking your HIV medication regularly, there are lots of things you can do to look after your physical and mental health including the food you eat, the amount of exercise you take and how you manage stress and difficult situations.

HIV Testing

There are significant benefits to being tested if you think you may have put yourself at risk of HIV infection. If you are HIV positive and remain undiagnosed, the virus may damage your immune system and compromise your future treatment options, so testing early means your health can be monitored carefully and anti-HIV drug treatment started when necessary. It may also influence the decisions you and your partner(s) may make about the type of sex that you have.

Testing for HIV involves screening a sample of blood (or sometimes saliva or urine) for antibodies to HIV infection. Antibodies are what the body produces to fight off infection. If you are worried about HIV and think you may have put yourself at risk, contact one of the services above to arrange getting tested. It may take between 6-12 weeks to develop antibodies to HIV following infection so you may be asked to return for a follow-up test 3 months later to ensure you receive an accurate result.

At the clinic where you have your test, a trained health professional will take a sample of blood from your arm or finger after explaining what will happen and how you will receive your results. In Sheffield results are usually available from most services 7-10 days after the test is taken. Quicker results are available through offers 'Point of Care' testing, with results from a finger prick blood spot available within 20 minutes. HIV test results are confidential and will not be shared with anyone without your permission.

If you and your partner have different HIV statuses (i.e. one HIV positive and one HIV negative), it is suggested that the partner who is HIV negative has a check-up once a year, or three months after engaging in unprotected sex or if a condom breaks/splits or comes off during sex. It is also important to be aware of the availability of PEP which, if taken soon enough, can prevent HIV infection from occurring following unprotected sex.

If you're worried about HIV and are considering testing, make a call to one of the services above and talk about your anxieties and concerns. Obviously the decision to test is your choice but testing early means your mind can be put at rest if the result is negative or your health and wellbeing can be monitored if the result is positive.

Newly Diagnosed

Being diagnosed with HIV can be challenging and raise lots of questions. Receiving a positive diagnosis can cause any number of emotional responses including surprise, anger, fear and shame, other people may feel emotionally numb – not knowing how to feel or react. It's really important for you to know that there is no 'right' or 'wrong' way to react, and that the main thing is for you to take the time you need to explore your feelings and to ask for the support you need to stay as healthy as possible.

When you receive a positive diagnosis, there are many options for help and support. At the time of testing you will be offered the opportunity to talk about your feelings about the diagnosis, and to ask as many questions as you might have about how your life will be affected. Don't worry if you forget to ask anything, or can't take everything in – this is to be expected – you can always ask again at another time when you are more able to take the information in.

For some people, receiving a positive diagnosis comes at a time when the virus has started to damage their immune system and they are feeling ill. The medical team might refer to this as a 'late diagnosis'. If you are diagnosed at this point it might feel overwhelming trying to take in all the information being given to you, your emotional state along with your physical health.

This can be a really difficult time and you might have a range of confusing feelings about your late diagnosis, but you should know that you are not alone – in fact the Health Protection Agency states that almost a third of all HIV positive adults in the UK received a late diagnosis, and this does not take into account all those living with HIV who do not know their status.

What is important is that while receiving a late diagnosis can be serious, and may require you to adapt to your diagnosis more quickly, you and your medical team can work closely to find the best treatment to support your health and wellbeing.

Mental Health & Emotional Well-Being

Anyone can be affected by emotional difficulties, or suffer from mental health issues at any point in their lives – recent research has suggested that one in every four people in the UK will experience some sort of mental health problem at some point in their lives, so it really isn't uncommon. However, living with long-term illnesses like HIV can mean that there is a greater likelihood you would encounter these problems for a host of different reasons.

Living with HIV can affect people in different ways. At times people can feel that they are coping and managing well. At other times people may feel anxious, stressed or depressed due to the way that HIV affects their lives. It is really important to look after your mental and emotional health and wellbeing as both have a significant impact on your ability to not only adhere and respond to your treatment regimes, but to also manage and get the most from your day-to-day living. There are various services in Sheffield that can offer a range of support for people living with HIV and offer pathways for treatment of depression, anxiety and other mental health issues.

Adjusting to diagnosis and treatment

Adjusting to a positive diagnosis can be a very challenging time, where emotional distress and feelings such as anger, guilt, fear, or shame can make it very difficult to think positively about the future, and to think about the options available for moving forward. For most people these feelings about having HIV change over time, and people gradually come to terms with being HIV+. However some aspects of living with HIV can still cause difficult feelings and some people may experience ongoing difficulties with low mood, depression and/or anxiety.

It's important to be able to recognise these difficult feelings and know that you have a right to feel this way. By acknowledging these feelings you can then begin the process of seeking help and support to overcome these difficulties.

Moving On

With the advancements in HIV treatment, more and more people living with HIV are living longer, healthier lives, and adapting their lives and relationships to look after their emotional, physical and mental health and wellbeing.

Many elements may contribute towards living well with a HIV+ diagnosis including:

- Accepting your own HIV status
- Having choice around disclosure of HIV status
- Positive relationships with partners, families etc
- Goals for the future
- Looking after your own physical health and wellbeing through healthy diets, rest and exercise
- Access to care and support
- Being in control of your own choices regarding alcohol, drug and tobacco use

Adapted from PANCAP resource:

HIV Anti-Stigma Toolkit for people living with HIV

Local Services

Support is available from the HIV Services in Sheffield in identifying and sustaining how you would want to move forward with your life, looking after your emotional, physical and mental health and wellbeing. Services in Sheffield can offer a range of help for people who have problems with depression, anxiety and other mental health issues.

Support in managing a positive diagnosis can be made through referral pathways from the point of receiving the positive diagnosis. Specialist Health Advisors at Sexual Health Sheffield and Specialist Nurses at E-Floor at the Royal Hallamshire Hospital are available to offer ongoing information and support based on an individual's needs. They can also answer questions about treatment options. Referrals can also be made through to specialist services such as Psychology Services and HIV Social Work support at the Forge Centre.

If you feel that you are experiencing low mood, anxieties or depression, it's really important to speak to someone about it, whether the Health Adviser at your next appointment, regular social work support or counselling, or even a close family member or friend. By asking for help in addressing these difficult feelings you may well be able to manage them much more effectively for yourself.

Information on this page has been sourced from 'HIV, mental health & emotional wellbeing' produced by NAM

Dealing with Stigma

Developments in treatments mean that more and more people living with HIV are living longer and healthier lives. However, the prejudice and stigma that many people have either directly experienced, or are concerned they may be subjected to, still presents major barriers to people living with HIV accessing the support, services and treatment that they need.

What is HIV related stigma?

HIV related stigmatisation has been identified as starting as soon as information regarding a person's sero-status is known (accurately or not). It is the process in which a person is looked at in many negative ways as soon as they are known or suspected to be HIV positive. (See Salvator Niyonzima, Understanding HIV Related Stigma)

"People who are stigmatised against are marked out as being different and stigma is often attached to things which are seen as embarrassing or a danger. Stigma can be used as a way of denying dignity, respect and rights to some members of society, and can result in people being isolated or abused. It can lead to discrimination, where people are treated less well because of a characteristic they have."

HIV & Stigma, NAM

Experiences or perceptions of HIV related stigma can have major effects on an individual if left unmanaged including:

- Increased anxiety and distress
- Distrust of services around issues including confidentiality
- Lower self-esteem and lack of confidence
- Lessened health and wellbeing
- Fear of criminalisation
- Lower expectations for self and others
- Feeling unable to disclose status to friends, families, work colleagues or partners

All of which have a significant impact, not only on a person's ability to access the treatment and support required, but also their ability to adhere to their treatment and care regimes.

Managing Stigma

Stigma and discrimination can be very difficult to challenge or manage and it is really important that you remember that you do not deserve to be treated this way and that it is unacceptable. If you then choose to challenge this treatment, you might want to consider the support, resources or information you might need to do this.

Know your rights: The Equality Act 2010

The Equality Act 2010 gives protection to disabled people from discrimination in a number of different areas, including employment and recruitment. HIV is considered to be a disability for the purposes of the Equality Act from the time of diagnosis. While this identification may in itself appear stigmatising – it does provide protection of rights for people living with HIV in key aspects of all our lives (i.e. housing, benefits, employment, goods and services).

Support

When we are faced with any difficulty it can be made that much harder if we feel we have to manage it by ourselves. It is often helpful if we are able to talk through any difficult feelings whether this is with families, partners, friends or colleagues. It can also be beneficial to access specific support services where specific Social Work support is available.

You may also find it useful to access peer support networks and HIV services which offer safe, confidential spaces to access one-to-one support and advice, time out from difficult situations, and the opportunity to share and learn from other people who have similar experiences or anxieties.

Complimentary Therapy

Complementary / alternative therapy is the term generally used for health practices or treatments that are not part of conventional western medicine or healthcare e.g. Reflexology, Shiatsu, Yoga, and Aromatherapy.

Some people living with HIV choose to use certain complementary therapies alongside their drug treatments in order to help reduce stress and anxiety levels, to relieve some of the side effects of conventional drug treatments, and to help with pain relief.

Complementary therapy refers to practices that are often used together with conventional medicine and drug treatments. There are many different types of complementary therapy.

These include:

- Massage - a physical therapy involving therapeutic touch to relax and relieve tension or pain.
- Aromatherapy – involving the use of essential oils and aromatic plant extracts.
- Reflexology - involving foot and hand massage.
- Shiatsu - a massage based therapy that focuses on energy flow in the body.
- Yoga - a physical therapy based on breathing exercises and forming specific body positions and postures.
- Reiki - a Japanese therapy that involves the therapist placing their hands on or above your body in order to channel your energy.
- Meditation - involving reflection or concentration to enable relaxation
- Acupuncture - involving puncturing the skin with needles in defined points to relieve the symptoms of certain conditions, such as pain.

Herbal remedies

Herbal remedies involve the use of plants or plant extracts to treat health conditions.

If you are considering using complementary therapy to help with reducing stress and anxiety levels, to relieve some of the side effects of your HIV drug treatments, or to help with pain relief, it's a good idea to talk to your consultant or specialist HIV nurse. Also check that the person offering complementary therapy is qualified and registered to deliver their specific therapy.

It is also important to understand that complementary therapy cannot replace your HIV drug treatments which have been prescribed to help manage your health.

Alternative therapy or medicine refers to practices used instead of conventional medicine rather than alongside it, and are more likely to be used in parts of the world where it is difficult to access Western medicine.

Because the current drug treatments used to treat HIV have been scientifically researched and tested and are very effective in reducing the impact of the virus, there is less demand for alternative medicine in the UK.

Some alternative therapies also claim to treat or cure HIV, but none have been proven to achieve this.

Again talk to your consultant or specialist HIV nurse about any questions or issues you may have about alternative therapies.

Healthy Eating

For people living with HIV, following a varied, balanced diet can support your immune system, promote a healthy heart, protect against some cancers, promote good bone health and help you achieve and maintain a healthy weight.

Food and water safety

Storing, preparing and serving food safely are important to minimise the risk of food poisoning for everyone. This is especially important if you are living with HIV and your CD4 count is less than 200.

Basic Rules:

- Wash your hands, utensils and work surfaces before handling food to ensure that they are all clean.
- Ensure all meat, poultry, fish and eggs are well-cooked and do not eat eggs that were cracked before being used.
- Ensure re-heated foods are piping hot throughout and never re-heat food more than once.
- Leave cooked food at room temperature for a maximum of 2 hours. Store cooked food in the fridge (preferably below 5°C) and do not use it if it has been stored for more than 24 hours. Cooked food may be kept for longer in the freezer (-18°C).
- Wash all fruit, vegetables and salads thoroughly.
- Do not eat mouldy foods, and ensure foods are eaten within their use by date.
- Store cooked and raw food in separate containers. Keep uncooked foods, especially meat and fish, below cooked/ready to eat foods in the fridge.
- When travelling abroad, ensure that the water is safe to drink. Also ensure water is safe when brushing your teeth or washing salads and any other foods.

If your immune system is low (CD4 count less than 200), you are more vulnerable to food poisoning so you need to take extra care:

- Avoid raw or rare meat and poultry, fish such as pink steaks, sushi and raw shellfish.
- Avoid undercooked eggs, or foods that contain raw eggs such as homemade mayonnaise, mousse or ice cream.
- Avoid using unpasteurised milk, cheeses such as brie, camembert and some brands of Parmesan and yoghurts.
- Avoid all pates.
- Drinking water in the UK is generally safe to use. However, due to accidents or filtration faults, it may become contaminated. If contamination is caused by micro-organisms in the water supply then:
- Boil water for at least a minute then store this water in clean containers in the fridge for a maximum of 24 hours. This is the best way to reduce your risk of picking up waterborne infections including cryptosporidiosis, a parasite causing diarrhoea.
- Use certified brands bottled water in sealed containers if you are unable to boil water.

Exercise

A healthy lifestyle which includes a healthy diet and regular exercise is beneficial to all. Research has shown that regular exercise can improve mood, body shape and measures of fitness in people living with HIV.

Benefits of Exercise

Exercise offers many benefits to your quality of life, general health and your HIV management, including:

- enhancing and strengthen the immune system, in turn helping to prevent or fight infections and speed up recovery from illness
- improving bone health; weight bearing exercise is especially good for strengthening bones
- strengthening your lung function and helping keep your heart healthy
- reducing breathlessness due to developing stronger heart and lung muscles
- improving mood
- improving body image/self-perception
- aiding weight loss in combination with a healthy diet

Before commencing any exercise programme, it is important that you discuss the best approach with your doctor.

Tips for exercising

- Be realistic, if you have never exercised before or haven't done for a long time then start slowly and build up gradually
- Exercising does not mean having to join a gym. Instead decide on exercise that you would enjoy and start from there
- Investigate exercise programmes in your local area, for example gyms, exercise classes, swimming, yoga, walking groups, tennis, basketball
- There are things you can do at home e.g. exercise DVDs, active computer games like dancing, walking up and down the stairs, active housework or gardening
- Think about exercise that fits in to your daily life for example walking or cycling to work, parking further away from work or the shops, taking the stairs rather than the lift
- Try to exercise with friends, this can be more fun and keep you motivated

GP Referral Programme

A GP referral scheme is available in Sheffield that offers access to specialist exercise programmes for patients with a variety of health conditions.

The GP referral scheme lasts for 12 weeks and is supervised by qualified fitness staff who will aim to ensure you have a safe, effective and enjoyable start to a more active, healthier lifestyle.

If you would like to participate in the exercise scheme talk to your GP, Practice Nurse, Consultant or other medical professional who will issue you with a referral form.

After you have completed your referral form, you will be contacted to arrange an appointment with a qualified instructor who will match you up with the best qualified staff to get the best results and work out the right exercise options for you.

All the instructors on the scheme are qualified to a minimum of YMCA Gym Instructor or equivalent, Level 3 Fitness Knowledge or equivalent, Exercise Referral Qualification (YMCA, Gayton, Wright Foundation) and BACR Phase 4 (for CHD Patients). Hillsborough Leisure Centre GP referral scheme is also accredited by Activity Sheffield.