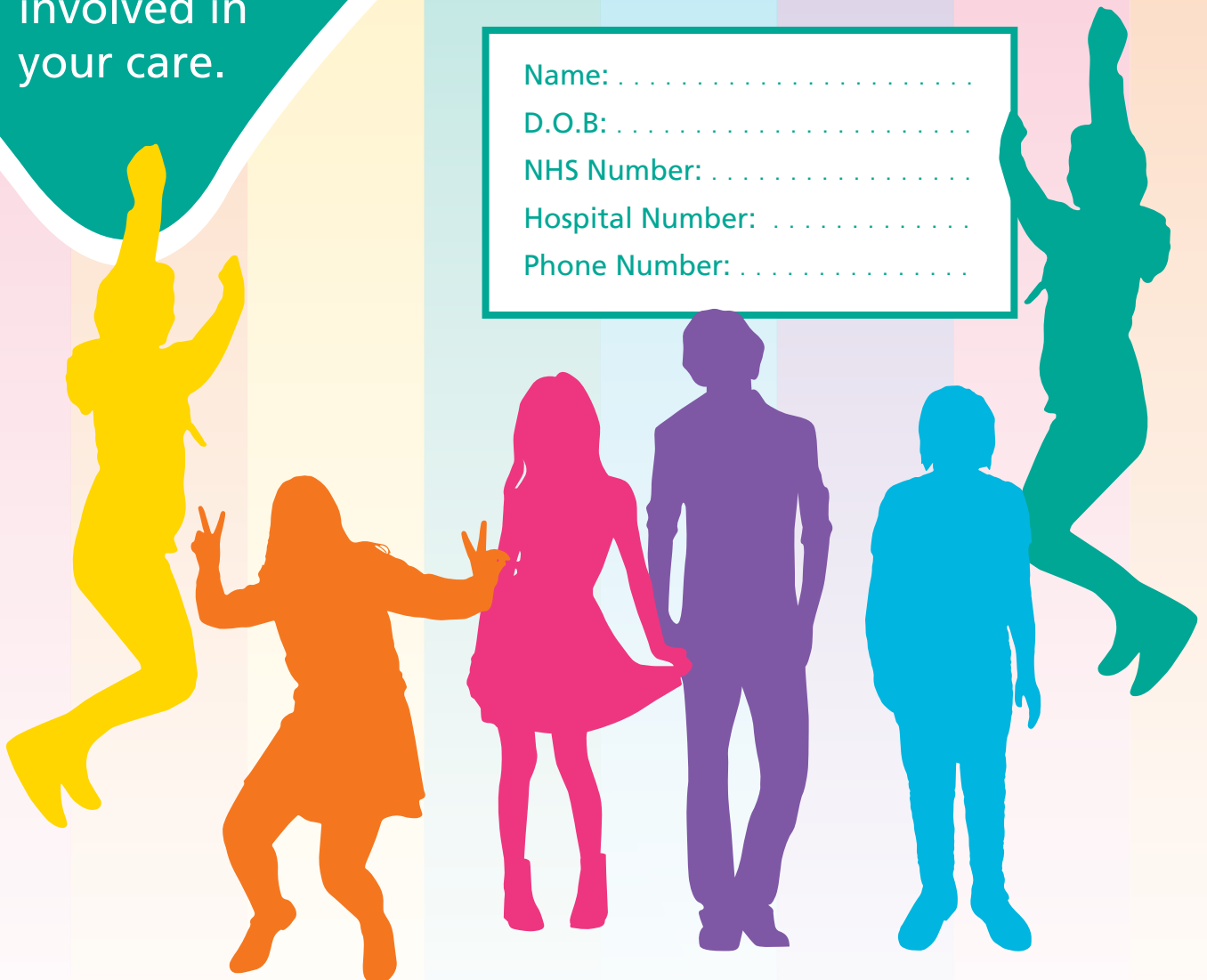


All about me

- Information and support for you and your health.
- An interactive tool to enable further discussion with professionals involved in your care.

Name:
D.O.B:
NHS Number:
Hospital Number:
Phone Number:



Contents

Topic	Date discussed /Initials	Date discussed /Initials	Date discussed /Initials	Comments
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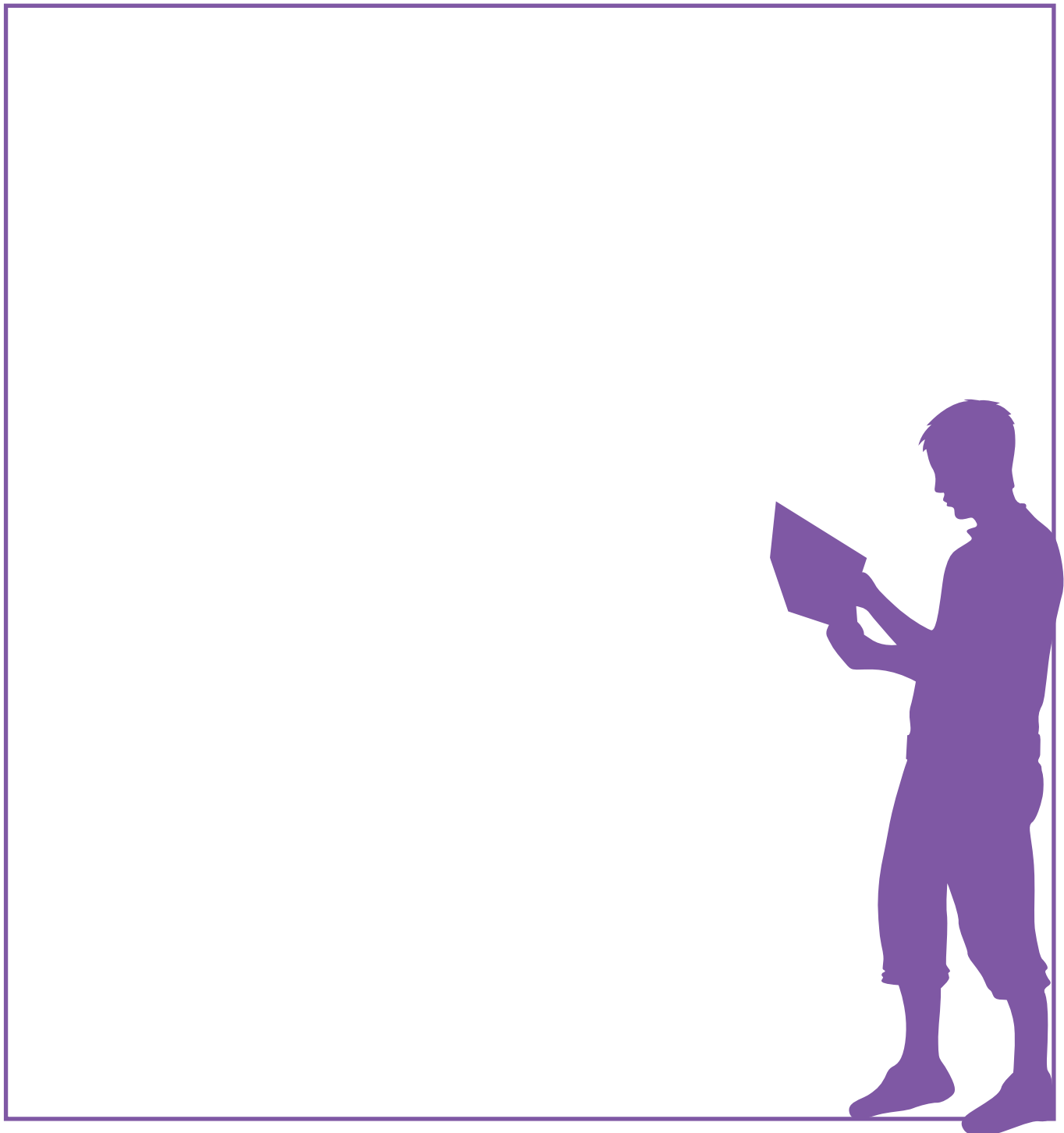
Topic	Date discussed /Initials	Date discussed /Initials	Date discussed /Initials	Comments
Sexual health				
What is sexual health?				
Sexual Health Services				
What is PEPSE?				
Is it illegal to pass on HIV? U=U				
Can I have children?				
Stigma and confidentiality				
What is stigma?				
What is confidentiality?				
How do I talk to people about living with HIV?				
What jobs can I do?				
Can I go on school trips, sleepovers and parties?				
What is a healthy lifestyle				
Exercise and Diet				
Alcohol and Drugs				
Emotional well-being				
Travel				
Groups and Peer Support				
Your Adult Clinic				
Useful resources				

What do you know so far?

Welcome to your new clinic pack! Inside you will find lots of information about why you come to clinic and who you will meet along the way. This is your very own pack and we will add to it together during your time with us. We can decide together whether your pack will be kept safe in the hospital or if you would like to take it home.

Let's see what you know already...

Use the space below to write or draw why you come to clinic.



Here are some reasons we like to see you in clinic...

To see how you are growing and to check that you are well.



Image by S.M

To talk about your health information that is private to you.



To ask how you are feeling.

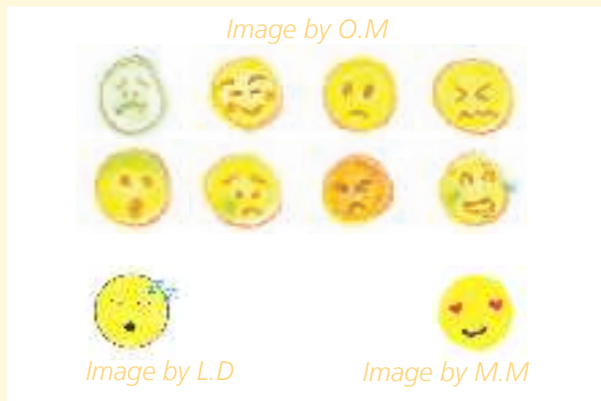


Image by O.M

Image by L.D

Image by M.M

To talk about any medicine you may be taking.



Image by G.K

To have a blood test.



To help you in other things that you do, for example, school, friendships and activities.



What's inside my blood?

When you come to clinic, you may be asked to have a blood test. This is so we can look closer inside your blood to help us know what is happening in your body. We use something called a microscope, which is a magnifying glass that makes tiny things look bigger.

Draw some things you think we might see in your blood if we looked at it under a microscope.

A large, empty rectangular box with a pink border, intended for a child to draw what they might see in their blood under a microscope.

These are some of the cells we see in your blood, let's talk about the very important jobs that they do:

- **Platelets** - these cells help our blood stick together after we have hurt ourselves.
- **Red blood cells** - these cells give us energy and carry oxygen around our body. This helps us to run and jump and play.
- **White blood cells** - these are our body's cells, that stop us getting unwell or help make us feel better.

Can you draw a picture of a white blood cell?

A large, empty rectangular box with a pink border, intended for a child to draw a picture of a white blood cell.

Did you know?

There are around
250 million red
blood cells in just
one drop of blood!

What else might be seen in my blood?

There may be other things in your blood. For example, a virus.

There are different types of viruses:

- Some stay in our body for a short time and make us feel unwell, like a cough and a cold.
- Others live in our body but don't grow or make us feel poorly.

You can't always tell when someone has a virus in their blood. This is because the virus can be very small and quiet and may not cause any problems, especially if you look after yourself and come along to clinic, just like you do!

What do you think a virus looks like?

Imagine we are having a look at your blood under a microscope, what would we see?



Did you know?

Have you ever had chicken pox? This is a virus that will always stay in your body even when your spots and itchy rash have gone away.

Did you know?

Some microscopes can magnify a virus up to 400 times its original size. Imagine looking at an ant the size of a building!

What is an immune system?

An immune system is the body's protection against different types of bacteria and viruses, that can make us unwell. Your white blood cells are part of the immune system. One type of white blood cell you will hear us talk about is the CD4 cells.

What do you think will help your immune system to stay strong and protect you?

Can you write or draw four things?

1

2

3

4

Did you know?

Laughter can boost
your immune
system!

Living with a virus

We know that viruses live in our body's and can be small, you wouldn't even know they were there. Sometimes viruses stay in our body's and because you have a virus that stays in your body, you come to see us in clinic. This means we can work together to help you stay well and make sure the virus stays small. Some people find it helpful to think of the virus as though it is asleep. Your immune system will need a helping hand to protect you and this is why you will need to take medicine every day.

Remember, people would never know the virus is there and living with it will not stop you going to school/ college, having fun or anything else you want to do!

What makes being you great?

Can you write or draw three things that you are brilliant at?

1

2

3

Time for a quick reminder

We have talked lots about your blood cells, your body, your immune system and your virus.

Can you have a go at answering some of these questions?

1. Why do I come to clinic?

.....

2. What is inside my blood?

.....

3. What else might be seen in my blood?

.....

4. What is an immune system?

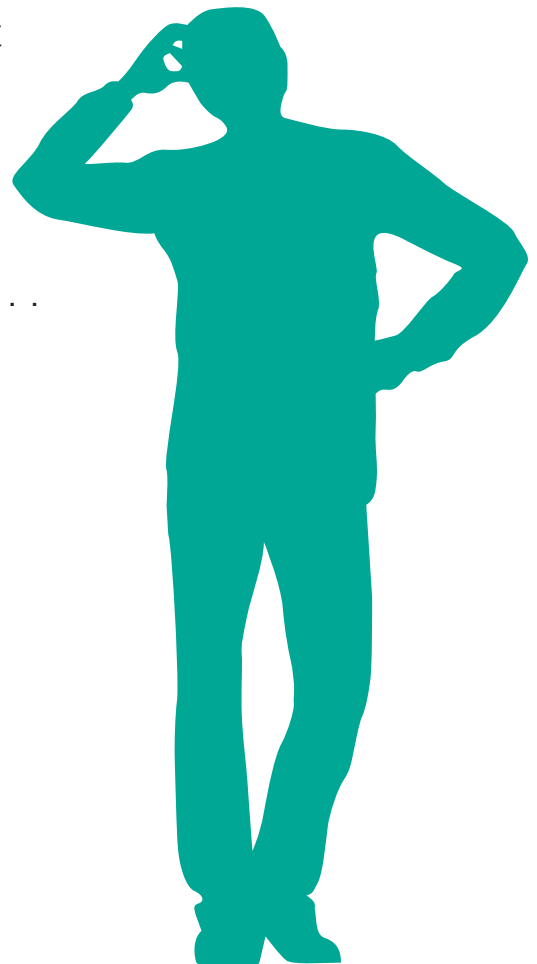
.....

5. What three things can you remember about your virus?

.....

.....

.....

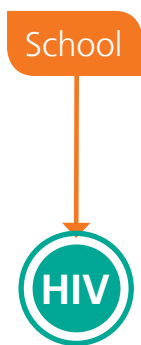


You now know the name of your virus

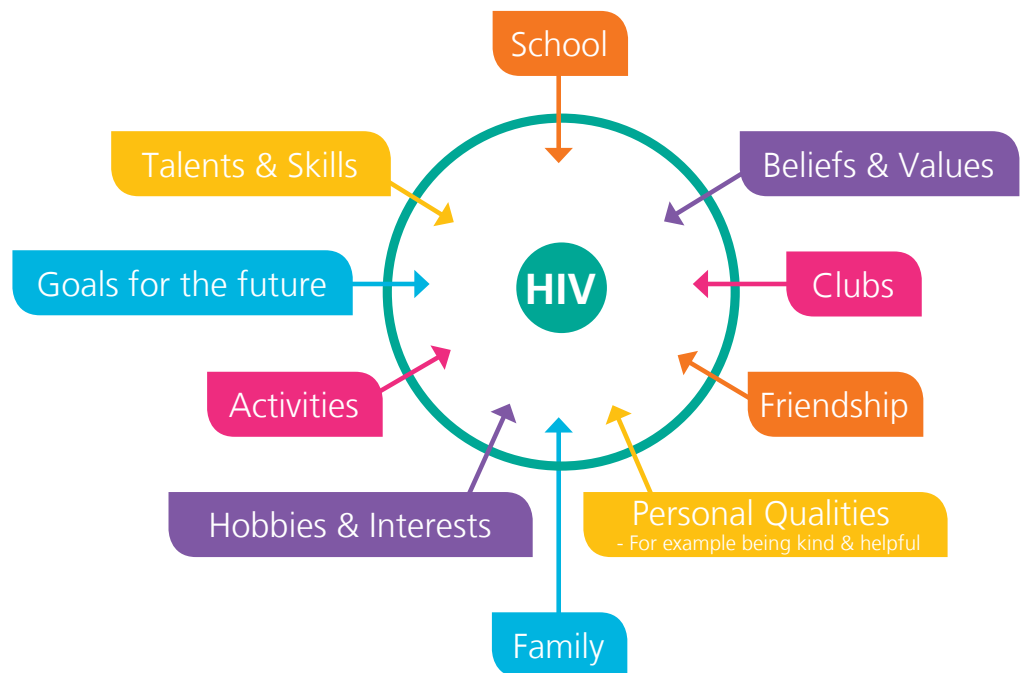
You now know that your virus is called HIV. As we have talked about together this stands for Human Immunodeficiency Virus and we will go into detail on the next pages. For now, it is important that you know, having HIV does not define you and you can live a long, happy and healthy life alongside HIV.

Have a look at the two diagrams. Person A and B both live with HIV. However, for Person B the HIV appears to be a smaller part of their life because of their focus on the many other things in their life.

Person A:



Person B:



Can you draw your circle which represents you, your life and the many things that are unique about you?

We love to hear about your talents, ambitions, hopes and dreams for the future!

A large, empty rectangular box with a teal border, intended for a person to draw their own circle representing their life and unique qualities.

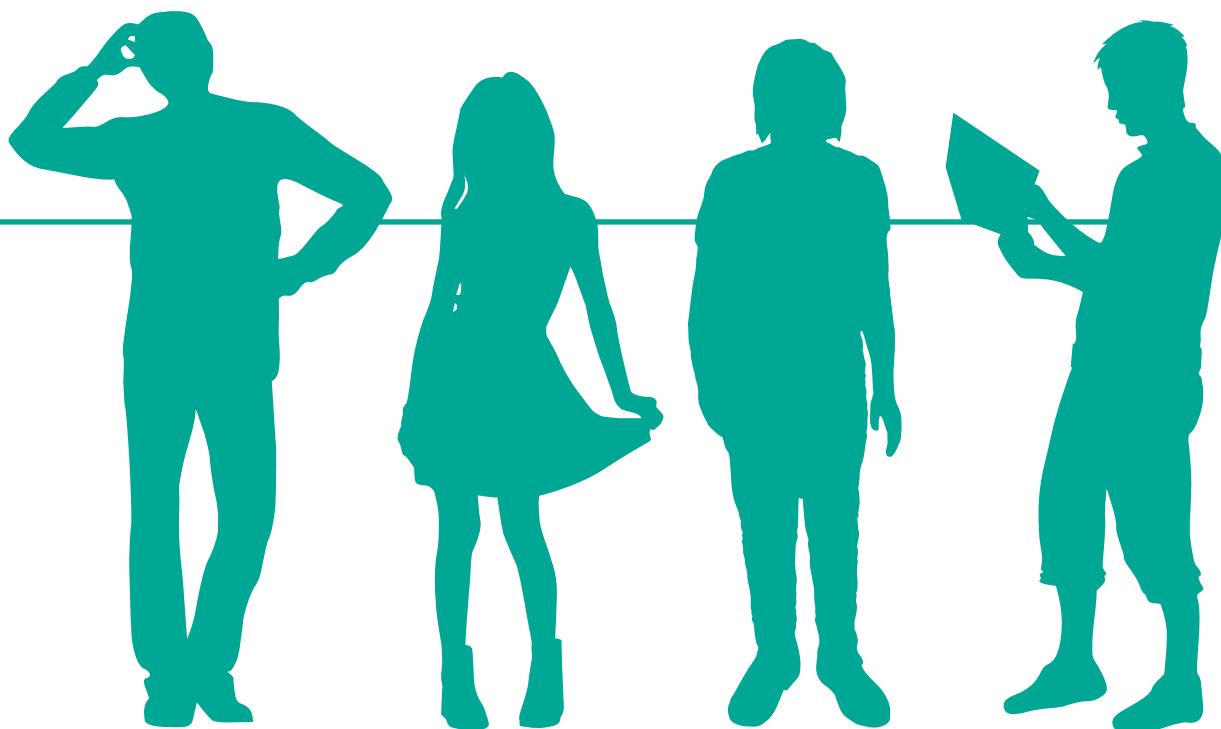
Now you know your diagnosis you may have some questions. Use the space below to write these down and remember...there is no such thing a silly question!

Did you know?

There are currently 801 children living with HIV in the UK (CHIPS data 2019).

Did you know?

There are approximately 89,400 people currently living with HIV in England, according to The Terrence Higgins Trust. Ask your clinic team about your local area



What do you know so far?

1. What do you understand by the term 'transition'?
.....
2. What does HIV stand for?
.....
3. Can you guess how many people are living with HIV in the world?
.....
4. What do you understand by 'viral load'?
.....
5. Can you describe what your 'CD4 count' is?
.....
6. How do your medicines work?
.....
7. Can you have a baby if you are living with HIV?
.....
8. Does living with HIV affect your career options?
.....
9. Does living with HIV affect your travel options?
.....
10. Who can you talk to about living with HIV?
.....
11. What do you understand by a healthy lifestyle?
.....
12. Do you think your emotional health is as important as your physical health?
.....
.....



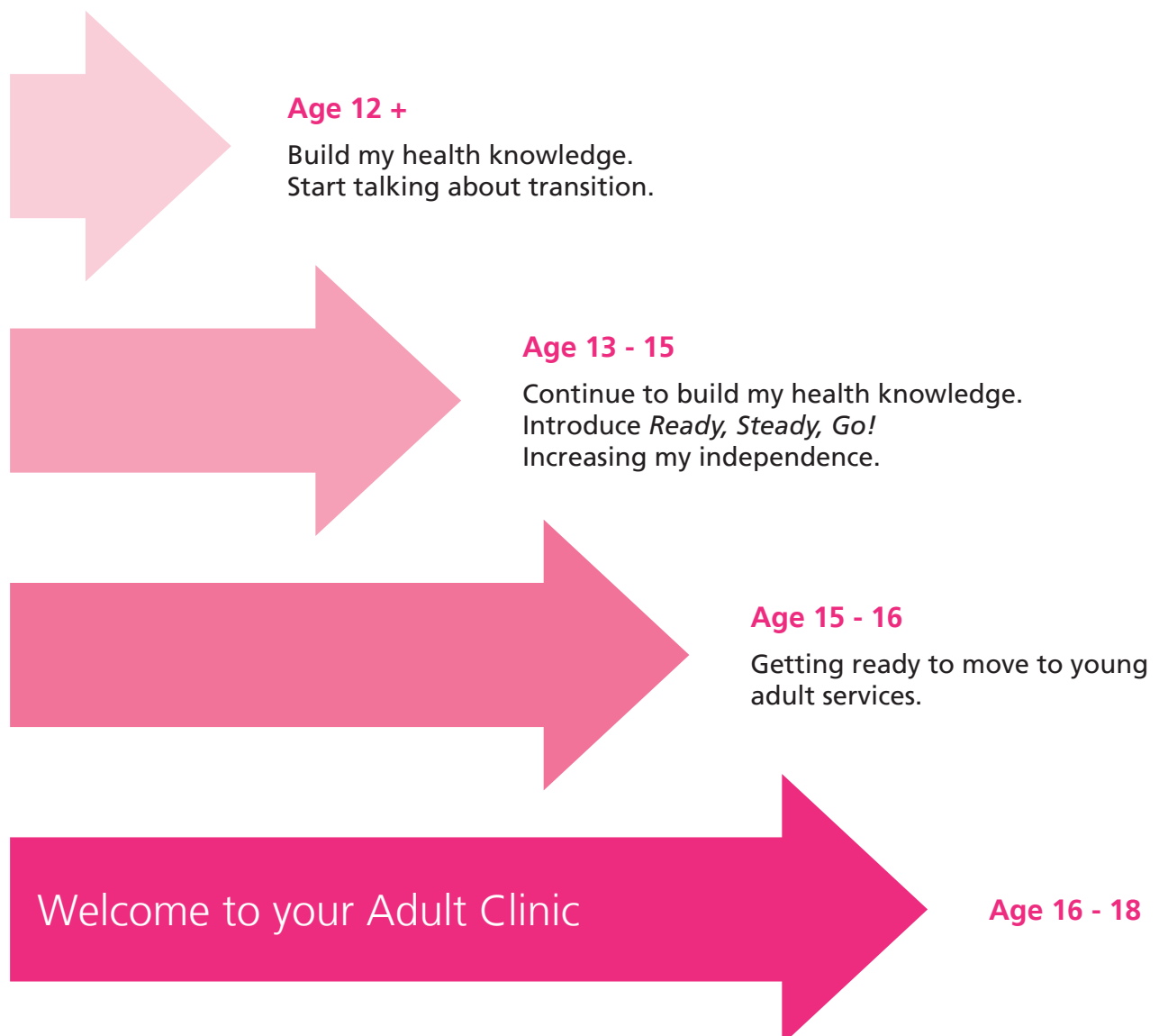
What is transition?

In healthcare, we use the word “transition” to describe the process of preparing, planning and moving from children’s services to adult services.

Transition is a gradual process that gives you, and everyone involved in your care time to get you ready to move to adult services and discuss what healthcare needs you will require as an adult.

Transition is about making plans with you – and not about you.

We understand that moving away from your team can sometimes feel scary but we hope that this pack and ongoing discussions with your team will help you feel more confident and happier about the move.



Transition Packs

In clinic we may go through a transition pack e.g. 'Ready Steady Go' with you at each visit. This is a really useful guide in getting you thinking about moving on and feeling prepared for adult services. There are different transition plans depending on which clinic you attend. Please discuss with your clinic team.

The Ready Steady Go transition programme - Getting Ready

The medical and nursing team aim to support you as you grow up and help you gradually develop the confidence and skills to take charge of your own healthcare. Filling in this questionnaire will help the team create a programme to suit you. Please answer all questions that are relevant to you and ask if you are unsure.

Name: _____ Date: _____

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I can describe my condition			
I know where to take my medications, when, how often, how often, etc.			
I know who's who in the medical and nursing team			
I understand the differences between paediatric and adult health care			
I know about resources that offer support for young people with my condition			
SELF ADVOCACY (speaking up for yourself)			
I feel ready to start preparing to be seen alone for part of the clinic visit in the future			
I ask my own questions in clinic			
I know what and where about Ask 3 Questions			
HEALTH AND LIFESTYLE			
I understand it is important to exercise for my general health and condition			
I understand the risks of alcohol, drugs and smoking to my health			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I develop e.g. puberty			
I know where and how I can access information about sexual health			

The Ready Steady Go transition programme - Steady

The medical and nursing team aim to support you as you grow up and help you gradually develop the confidence and skills to take charge of your own healthcare. Filling in this questionnaire will help the team create a programme to suit you. Please answer all questions that are relevant to you and ask if you are unsure.

Name: _____ Date: _____

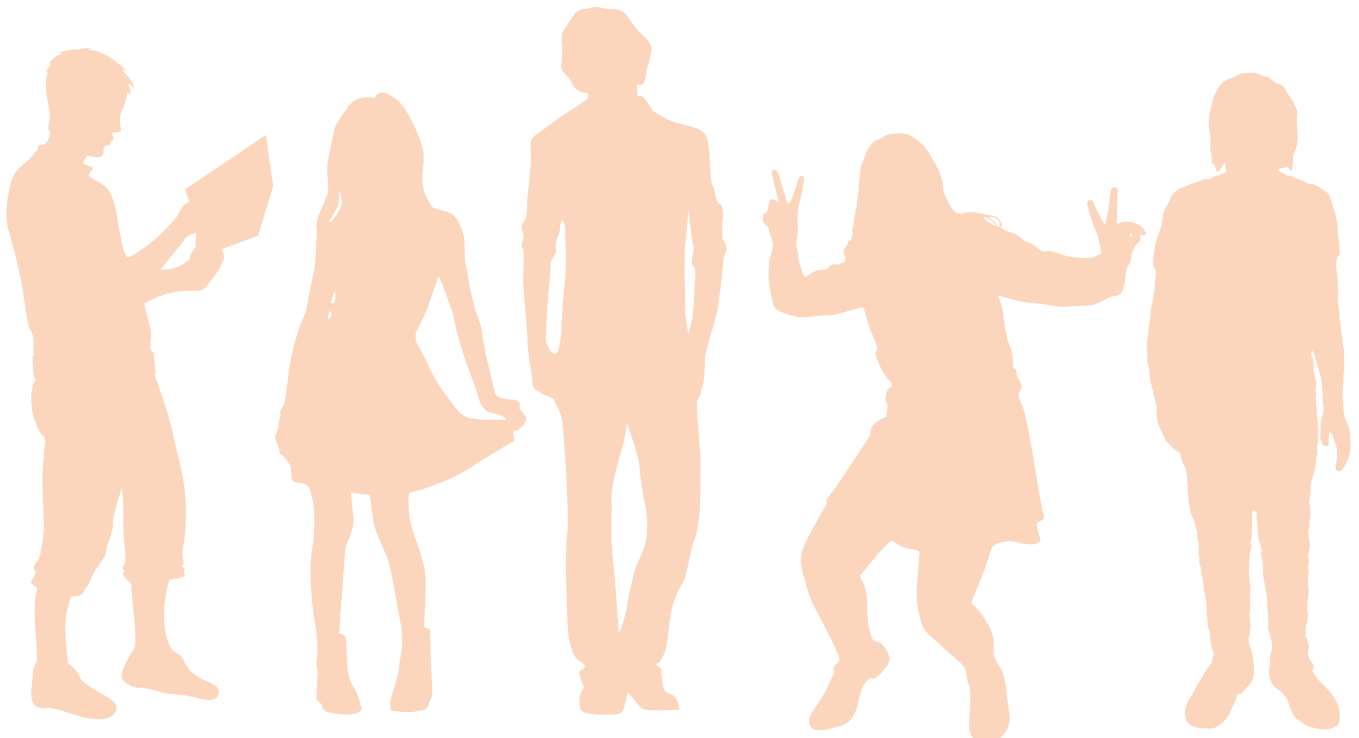
Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I understand the medical terms/words and procedures relevant to my condition			
I understand what each of my medications are for and their side effects			
I am responsible for my own medication at home			
I order and collect my repeat prescriptions and book my own appointments			
I call the hospital myself if there is a query about my condition and/or therapy			
I know what each member of the medical team can do for me			
I understand the differences between paediatric and adult health care			
I know about resources that offer support for young people with my condition			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own for some/all of each clinic visit and to ask my own questions			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team e.g. Ask 3 Questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/have an active lifestyle			
I understand the risk of drugs, alcohol and smoking to my health			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I develop e.g. puberty			
I know where and how I can access information about sexual health			
I understand the implications of my condition and drugs on pregnancy/parenting			

The Ready Steady Go transition programme - Go

The medical and nursing team aim to support you as you grow up and help you gradually develop the confidence and skills to take charge of your own healthcare. Filling in this questionnaire will help the team create a programme to suit you. Please answer all questions that are relevant to you and ask if you are unsure.

Name: _____ Date: _____

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I am confident in my knowledge about my condition and its management			
I understand what is likely to happen with my condition when I am an adult			
I look after my own medication			
I order and collect my repeat prescriptions and book my own appointments			
I call the hospital myself if there is a query about my condition and/or therapy			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own at clinic			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team e.g. Ask 3 Questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/have an active lifestyle			
I understand the effect of smoking, drugs or alcohol on my condition and general health			
I understand what appropriate eating means for my general health			
I know where and how I can access information about sexual health			
I understand the implications of my condition and drug therapy on pregnancy/parenting (if applicable)			
DAILY LIVING			
I am independent at home - dressing, bathing, showering, preparing meals, etc.			
I can or am learning to drive			



Your Paediatric Team

Throughout your time in clinic you will meet different members of your paediatric team, do you know who everyone is? Can you write down their names and contact details?

Name:

Contact Details:

.....

Description of role: (ask your Health Care Professional what their role involves):

.....

.....

.....

.....

.....

Name:

Contact Details:

.....

Description of role: (ask your Health Care Professional what their role involves):

.....

.....

.....

.....

.....

Name:

Contact Details:

.....

Description of role: (ask your Health Care Professional what their role involves):

.....

.....

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.....

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Name:

Contact Details:

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Description of role: (ask your Health Care Professional what their role involves):

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Name:

Contact Details:

.....

Description of role: (ask your Health Care Professional what their role involves):

.....

.....

.....

.....

.....

Name:

Contact Details:

.....

Description of role: (ask your Health Care Professional what their role involves):

.....

.....

.....

.....

.....

Your Adult Team

Throughout your time in clinic you will meet different members of your adult team, do you know who everyone is? Can you write down their names and contact details?

Name:
Contact Details:
.....

Name:
Contact Details:
.....

Name:
Contact Details:
.....

Name:
Contact Details:
.....

Name:
Contact Details:
.....

Name:
Contact Details:
.....

What is HIV?

HIV stands for: **H**uman **I**mmunodeficiency **V**irus

Human just means people.

Immunodeficiency is when our 'immune system' (how our body fights off illnesses) is not working as well as it could.

Virus is a really small organism that can live in the blood and can only be seen under a microscope.

You may have also heard of the term **AIDS** - This stands for **A**cquired **I**mmune **D**eficiency **S**yndrome. This is when the immune system is very weak and a person gets illnesses and infections that wouldn't happen when the immune system is strong. This is very rare because medicines work really well.

As you will know, without your medicines you can become unwell. This is because the HIV virus can multiply (make copies of itself), which means it takes over a healthy immune system. Medicines work brilliantly when you take them every day. Doing so helps you to keep well and live a long, healthy life.

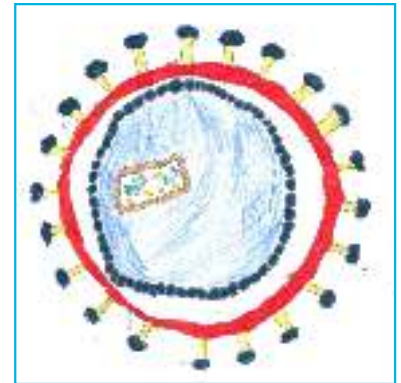


Image of a HIV cell by F.K



What is viral load?

Viral load is the number of copies of the virus per ml of blood.

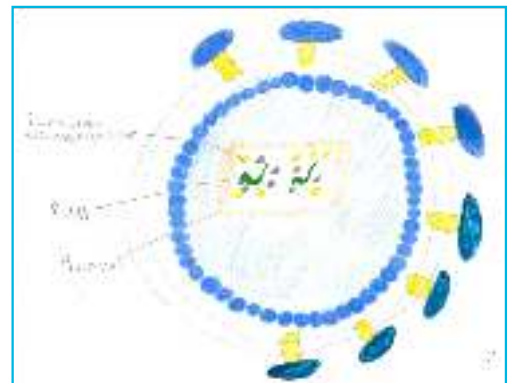
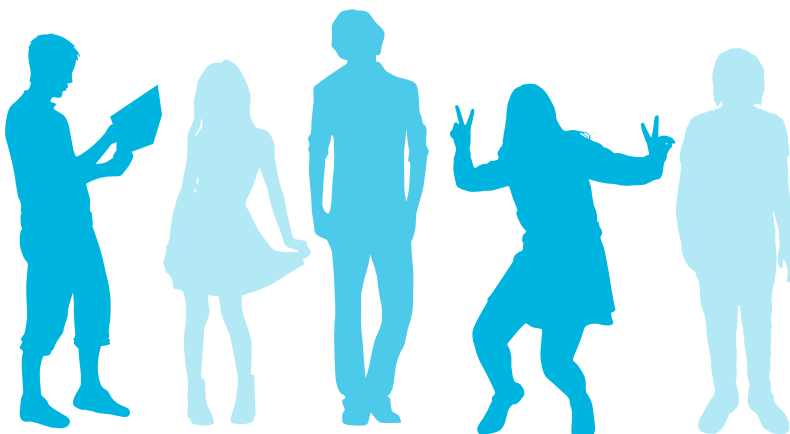


Image of a HIV cell by M.K



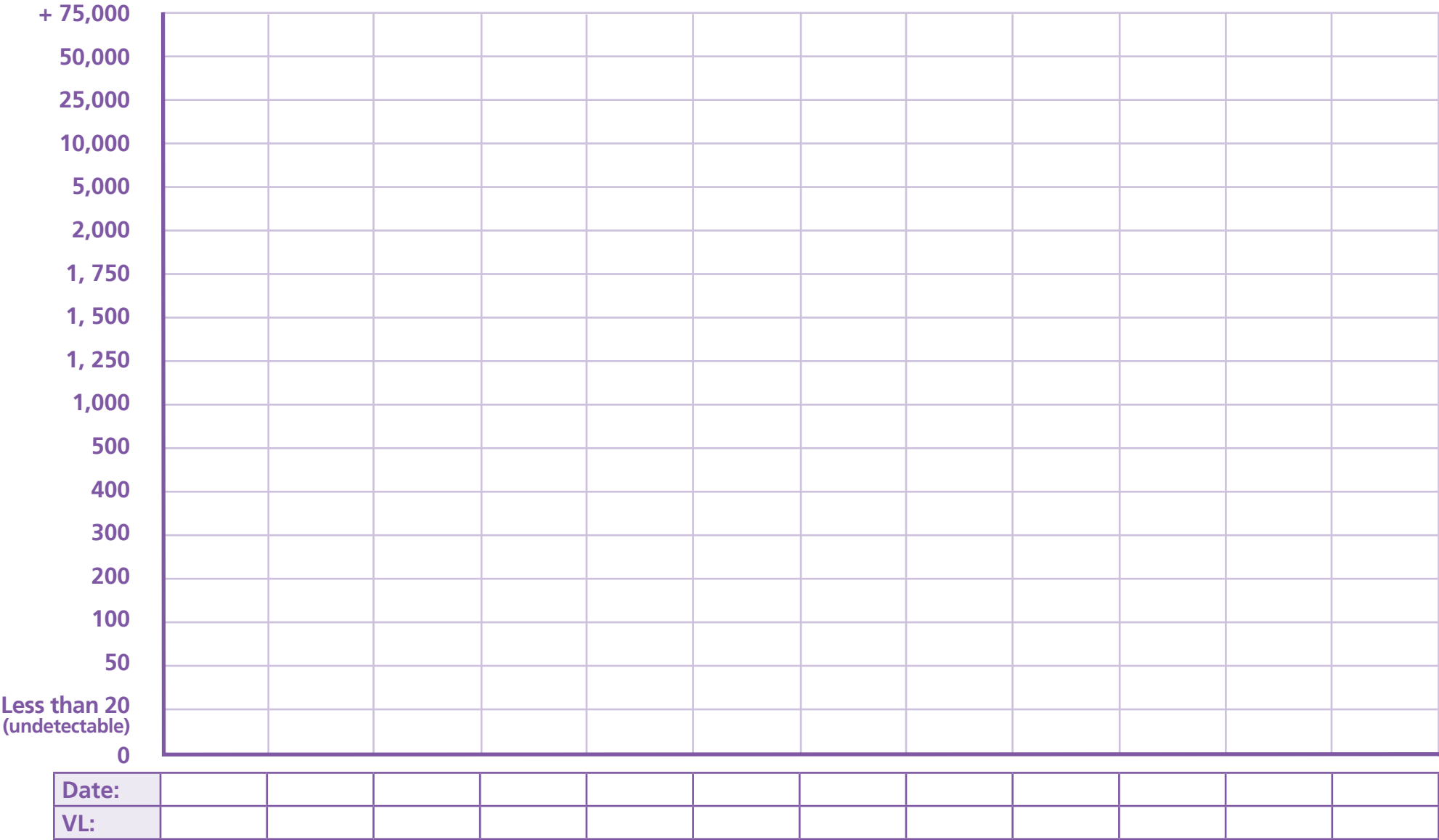
What is a CD4?

CD4 is a type of white blood cell, you may remember we have called these white blood cells. The CD4 cells protect your body from infection.



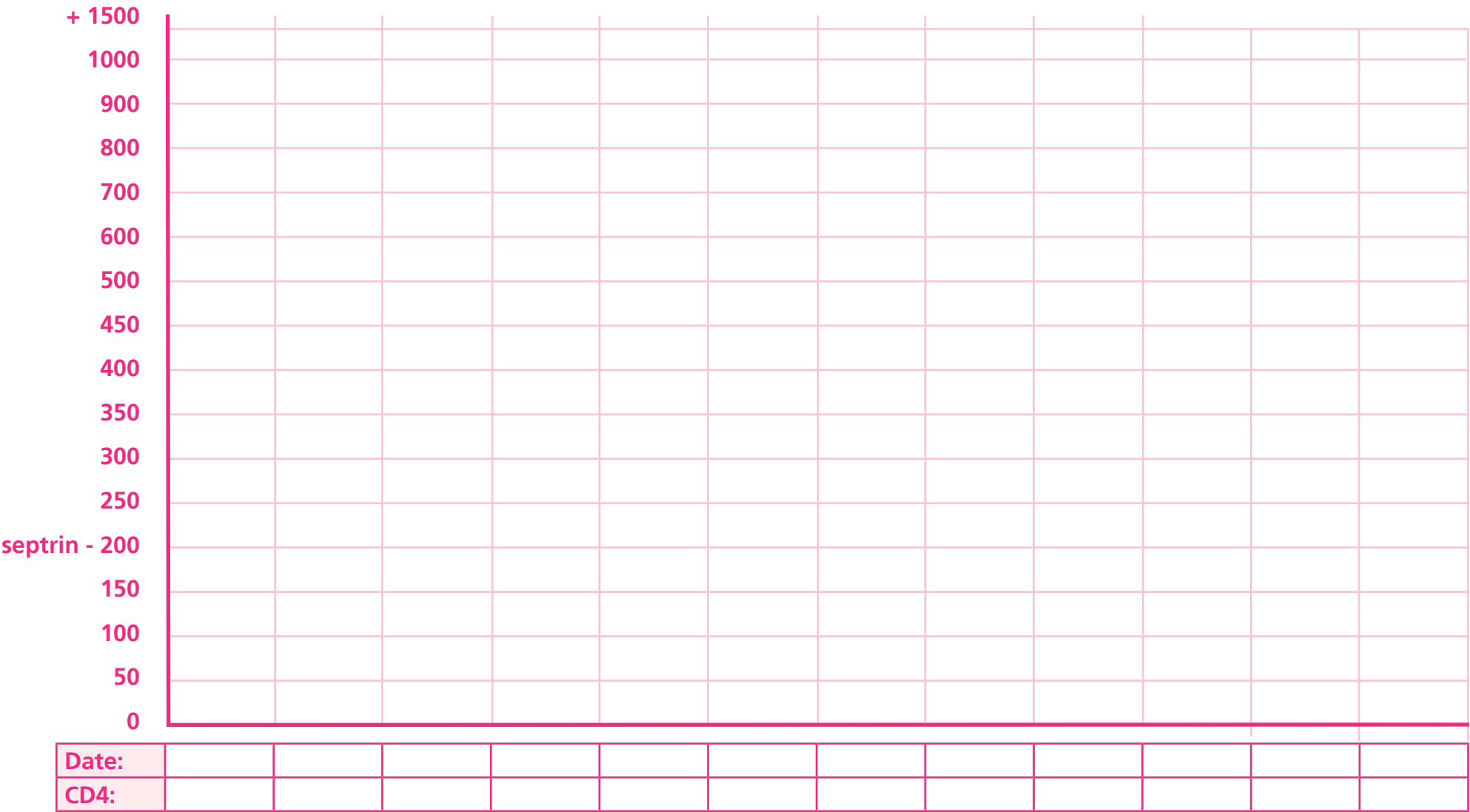
My results chart - Viral load

Please plot your results on the chart below.



My results chart - CD4

Please plot your results on the chart below.



How do my medicines work?

Medicines do a really good job of stopping HIV reproducing. We know that HIV can enter CD4 cells, make more virus and cause CD4 cells to drop. Antiretroviral medicines work by stopping the virus entering CD4 cells which means the virus can't reproduce, therefore, keeping the virus at low levels. You may remember we have talked about your viral load and when this is at tiny levels, known as undetectable (the machine in the laboratory can not detect the virus as it is at such low levels), you have more CD4 cells. This means your immune system is working brilliantly!

What is my medication history?

Dates	Medicines



Image by G.K

Did you know?

There are free downloadable apps to help remind you to when it's time to take your medicines. Please ask your clinic team for details.

What is adherence?

Adherence means following professional health advice. We are all encouraged to do this, for example, following medical guidelines about eating enough fruit and vegetables, drinking water and exercising to stay well. Sometimes we are good at adhering (following advice) and sometimes it is harder to do.

When we talk about adherence to your medicines, this means following the advice of your medical team about when, where and how best to take your medicines. Adherence is very important because when you take your medicines the HIV is very well controlled (undetectable). However, if you miss any doses this will mean there will not be enough medicine in the body to stop HIV reproducing.

We all forget things from time to time, life can be very busy. It is understandable that there may be times you will miss your medicines or take them later than advised. Sometimes this may be a one off, however if you are regularly missing your medicines, for example, missed doses every week, please make sure you talk to your clinic team.

Did you know?

If you are struggling to swallow your medicine, please talk to your clinic team as they have lots of top tips!

Here are some reasons taking medicines can be difficult. Have you ever struggled with any of the following four key areas? If so, tick the statements that most apply to you.

Feelings

- ☐ I don't want to think about having HIV
- ☐ I'm stressed. I have other things going on in my life
- ☐ I already have too much to do with school / college and my exams
- ☐ I feel overwhelmed
- ☐ I don't like feeling different to my friends
- ☐ I'm not comfortable taking medicines in front of people
- ☐ I'm just bored with taking my medicines

Practical

- ☐ I don't want to take them when I'm at sleepovers or parties
- ☐ I don't have a set routine
- ☐ It's hard to remember when on holidays or away from home
- ☐ It's not easy to store my medicines
- ☐ There are food restrictions
- ☐ I don't always have access to drinks and snacks that help
- ☐ I struggle when I don't have support

Adherence

- ☐ I am influenced by my families views and experiences in taking medicines
- ☐ I am curious about what might happen when not taking medicines
- ☐ I have certain beliefs about HIV
- ☐ I have certain beliefs about medicine and its benefits

Beliefs

- ☐ I don't like the taste
- ☐ I don't like the side effects
- ☐ My medicines make me feel unwell
- ☐ I have difficulty swallowing them
- ☐ I just keep forgetting
- ☐ It's hard when I feel unwell or tired

Physical

Young people's top adherence tips!

The young people of the Together 4 Life group in Leeds came up with these tips to help when taking HIV medicines:



Which tips would be helpful for you?

Do you have any ideas you would like to share? If so, fill in the empty speech bubbles.

What do the young people of CHIVA say about taking medicines?

CHIVA (The Children's HIV Association) is a registered charity working across the UK and Ireland improving care for children and young people living with HIV and their families. CHIVA provides information, guidance and support for professionals, parents and young people living with HIV and runs an annual support camp for HIV positive young people.

CHIVA have a fantastic website with lots of free resources, top tips and hints especially for young people who want to know more about living with HIV. Go to <http://www.chiva.org.uk> and have a look!

Here are what some of the young people of CHIVA said about the positive aspects of taking medicine:

"Makes it more difficult to pass HIV on to others when you take your HIV medicine"

"Keeps your immune system healthy and your HIV virus low"

"Keep an emergency supply where you might need them"

"Take your medicines with something that tastes good to disguise the taste"

"Helps you live a normal life"

"Use an alarm on your watch or mobile phone as a reminder"

"Ask your clinic staff for a weekly pill box/dosette box"

"Medicine prolongs your life"

"Reward yourself with a treat when you have done well"

"If you think you have any side effects, your clinic team will help you"

"Be involved in making decisions about your treatment"

"Have an answer ready just in case someone asks why you are taking medicines"



What is drug resistance?

Did you know?

Once resistance has occurred it will always be there and will limit your future treatment options.

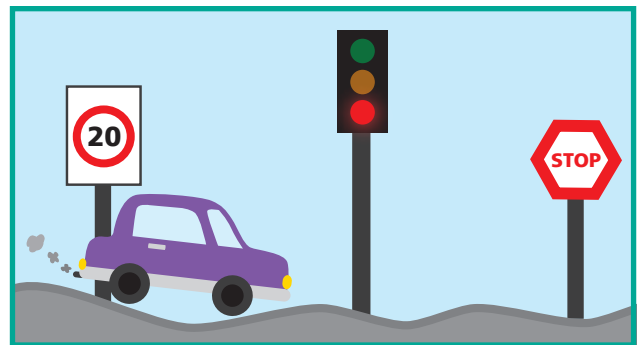
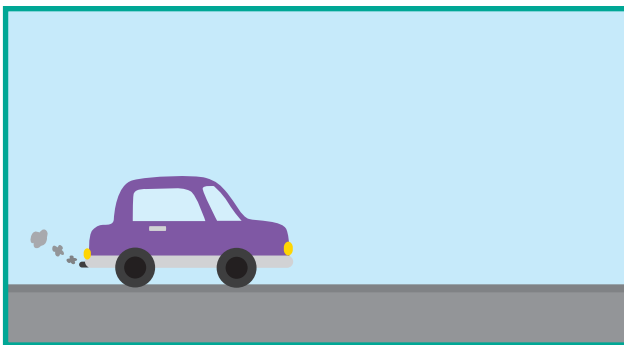
Resistance is when something slows down and stops working as well as it should. Sometimes this happens with medicines and is known as drug resistance. It occurs when the virus changes its structure in a way that stops the medicine from working. These changes are called 'mutations'. There is a risk of resistance when your medicine levels drop. This can be as a result of incorrect doses (e.g. while you are growing) or missed doses (e.g. forgetting). If your viral load increases on treatment this could be as a result of drug resistance.

How can I avoid resistance?

As we have talked about previously, taking medicines as advised by your clinic team is important. This is also the best way to avoid resistance. This will allow your medicines to work for many years.

Resistance can be difficult to understand at first. Read the story below and think about the various obstacles that prevent the car from working as it should.

Imagine you are on a long car journey. It a nice calm day and the road ahead is clear. As you travel along you notice the road gradually starts to get bumpy and obstacles begin to appear. You are running low on petrol but decide to continue your journey without filling up. Further along the road you come to a speed restriction which slows you down, then a red light and finally a large



stop sign. Your journey comes to an end and you can no longer travel on that particular road.

Within this story...

- The car represents a person living with HIV
- The petrol represents the medicine
- The bumpy road with different obstacles along the way represents resistance, which stops the car moving as effectively as it should.

Did you know?

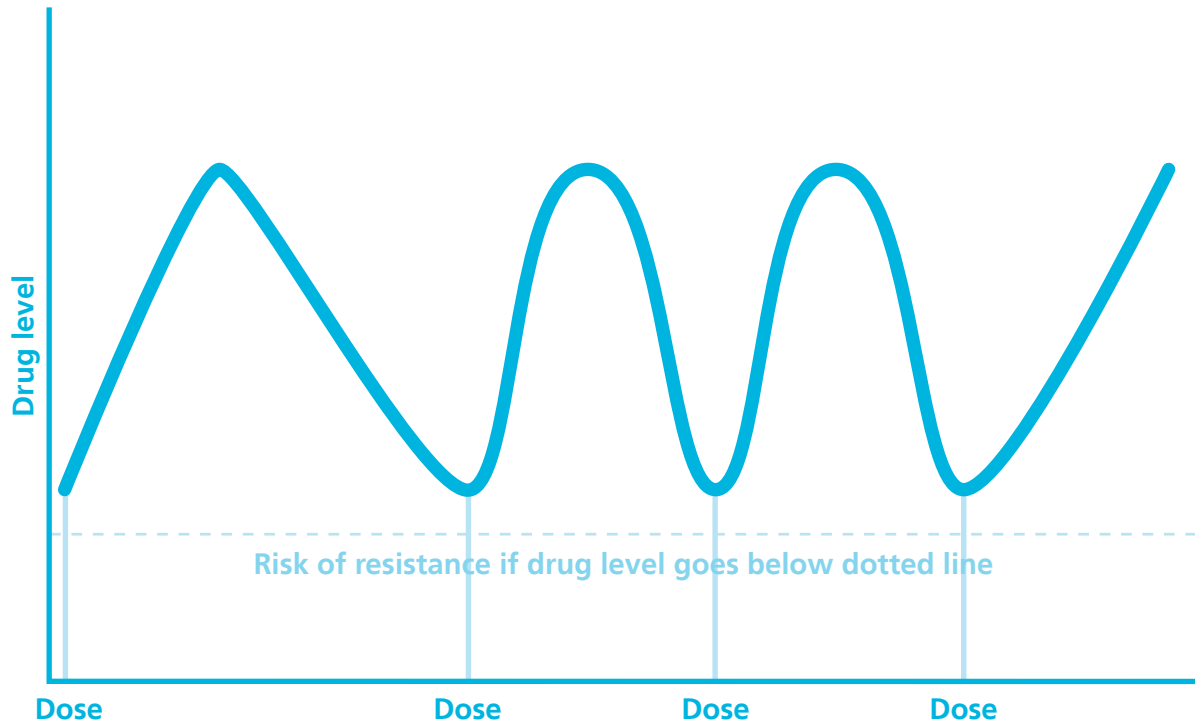
Having an undetectable viral load (less than 20 copies/ml) removes the risk of resistance

So, by taking medicines every day you can continue your journey to wherever you want to go!

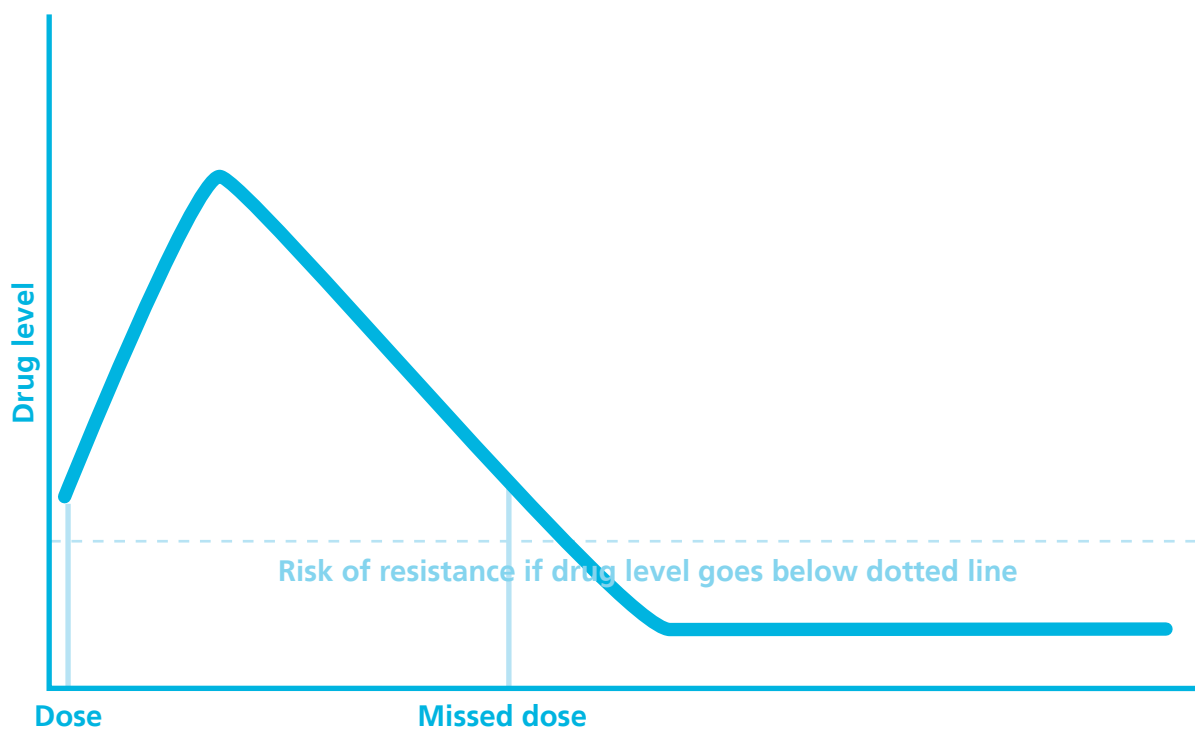
Your resistance results

Resistance explained

Drug levels with good adherence



Missed / Late dose



What is sexual health?

Sexual health is something that affects us all. It's about looking after yourself and others. When we talk about 'sex', this includes topics such as being safe, contraception, enjoying healthy relationships, your gender, having feelings about another person and being intimate with them.



Have you considered the impact of sharing inappropriate images online and the consequences associated with this?

Sexual Health Services

Sexually transmitted infections (STI's) are infections that can be passed from one person to another person during sexual activity.

Chlamydia, Gonorrhoea, Genital Herpes, Genital Warts, Pubic lice and Syphilis are some of the STI's you may have heard about.

STI's can be passed on through all types of sex:

- Vaginal
- Anal
- Oral sex

STI's can be spread through any contact with the penis, vagina, anus or mouth - even if there is no penetration. STI's can affect anyone who is having sex whether you're straight, gay, lesbian or bisexual.

What do I need to look out for?

Some people may have very obvious symptoms which could include:

- Rashes and itches around the vagina, penis or anus
- Lumps, sores and growths around the vagina, penis, anus or mouth
- A smelly or unusual discharge from the penis or vagina
- Pain when going to the toilet
- Pain when having sex

Some STI's may have no symptoms at all but can cause damage to our bodies.

How do I get tested and treated?

Many STI's are curable and all are treatable - so if you think you have an infection or you have had unprotected sex (sex without using a condom), talk to us in clinic or visit one of your local and confidential sexual health services.

Did you know?

70% of females with Chlamydia experience no symptoms at all.

Your sexual health services

Address:

Phone number:

Opening hours:

What is PEPSE?

Post Exposure Prophylaxis after Sexual Exposure (PEPSE) is anti HIV medicine that can be given to a HIV negative partner to prevent transmission following a risky situation. E.g. if a condom breaks or you have forgotten to use one.

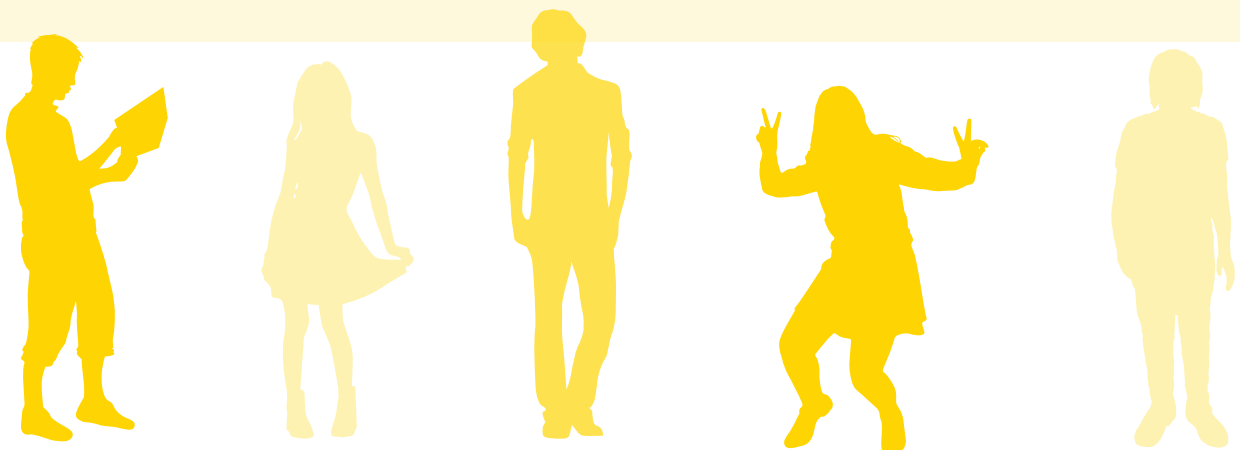
The risk of passing HIV to your partner is much lower if you are on anti HIV medicines and your virus is undetectable. Should a condom break, you are both protected but it is still important to think about STI's, which may increase the risk of transmission in this situation.

What do I have to do if a condom breaks, slips off or I have forgotten to use one?

1. Tell your partner you have HIV. This can be difficult and your clinic team will be able to help. There is also advice and guidance in this booklet on the page titled 'how do I talk to people about living with HIV?'.
2. Your partner will need to attend *your* local sexual health centre.
3. The quicker you follow this advice the better! We recommend you seek advice ASAP and no later than 3 days after sex.
4. Should your partner need PEPSE, they will have to take this medicine for four weeks.
5. If you are undetectable refer to U = U information on following page

Your personal plan:

Please insert your personal PEPSE plan:



Is it illegal to pass on HIV?

If you practice safe sex (as described on page titled 'What is sexual health?') then you are not breaking any laws. However, unfortunately, some people have gone to prison because of something called 'reckless transmission'. This is when a person living with HIV has knowingly not protected their sexual partner and transmission has occurred.

The law is only broken if **all** of these points apply:

1. You know you have HIV
2. You know how HIV is transmitted
3. The person you have sex with doesn't know that you have HIV
4. You have sex without a condom
5. You pass HIV on to the person you had sex with

For up to date information on transmission and the law and reckless transmission visit: www.aidsmap.com and the CHIVA website: <https://www.chiva.org.uk/youth/hiv-facts/hiv-and-law/>

U=U (Undetectable=Untransmittable)

U=U means you are taking antiretroviral medicines and you have an undetectable viral load. Therefore, you haven't missed any doses of your medicines and your HIV has been under control for more than 6 months.

Recent research (The PARTNER Study, 2016) explored 58,000 instances of sex without a condom between partners (one partner HIV positive, one partner HIV negative). You may be encouraged to learn that results showed that when the HIV positive partner was undetectable, there were **zero** cases of HIV transmission.

What do you think about this finding?

What does it mean for you?

You may find it useful to chat further about U=U with your clinic team or visit the CHIVA website for more information - <https://www.chiva.org.uk/professionals/uu/>

Can I have children?

Absolutely! HIV should not stop you achieving your life goals. You can have a family and importantly, you are very likely to be able to have a child who doesn't have HIV.

When you're living with HIV you can have a child with a negative partner without transmitting HIV. Your clinic team can help you with options when considering having a baby.

Taking medication is vital to having healthy children and being a healthy parent.

Did you know?

There are specialist HIV health professionals who can support you and your partner throughout pregnancy.

Did you know?

Every year in the UK many babies are born to women who know they are HIV positive and almost all of these babies do not have HIV.

Did you know?

Your baby will be closely monitored once it is born. Usually by the time they are aged 3 - 4 months and after three negative blood tests, we are confident that they will be HIV negative. Your baby will continue to be monitored until they are 18 months old.

What is stigma?

Stigma is the strong feelings we have about someone, something or ourselves. Often stigma occurs when people make a judgment based on beliefs, wrong information and misunderstandings rather than knowing the true facts. Unfortunately, there can be a stigma towards people with certain health conditions, including those living with HIV. For example, some may assume that they will get HIV through touch, sharing cutlery and using the same toilet seat, even though we know these views are not correct.

What do you think different people might say or think about HIV?
Fill in the speech bubbles below:



Image by A.C



Image by A.C

Did you know?

Sometimes people wrongly assume that people living with HIV are to blame for their condition, however, HIV does not discriminate it can affect us all.

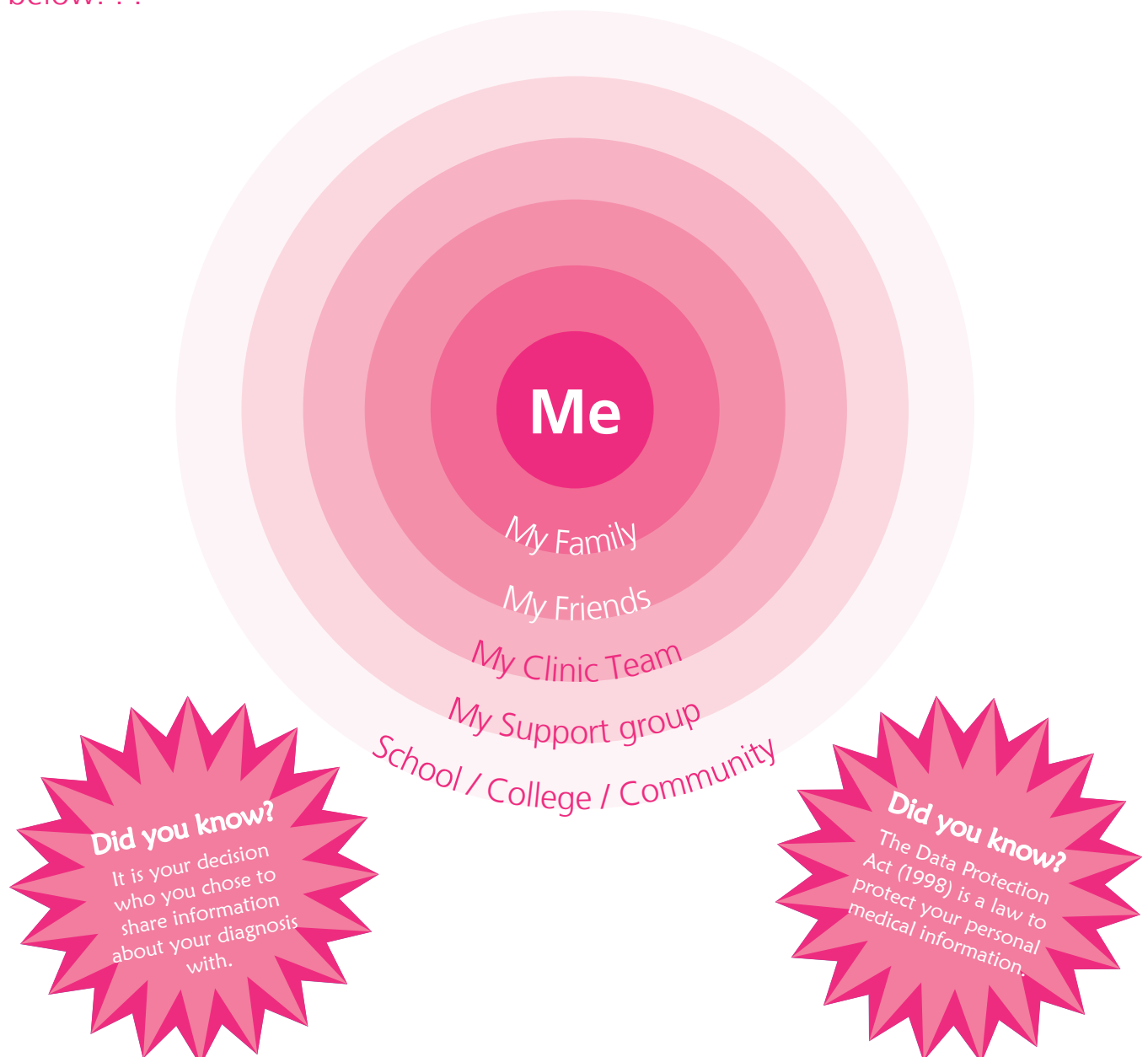
What is confidentiality?

Confidentiality is the right for information about you to be kept private. We all have information that we would not want other people to know about without giving our consent (permission) first. For example, when talking to a GP about our health, the information we share is private and therefore the conversation must be kept confidential. However, when there are serious concerns, confidentiality can be breached.

What are your views about confidentiality?

What would you do if you found out that someone had shared information without your permission?

Put the names of the people who know that you live with HIV in the circles below. . .



How do I talk to people about living with HIV?

It can be difficult to share personal health information with others, even more so when there is a stigma attached to a health condition. Sometimes people choose to talk to a family member or a close friend they can trust, although it can be difficult to work out who to tell, how to start a conversation and what their reaction will be.

Here are some helpful questions to consider before talking to others about living with HIV:



Tricky things about sharing your diagnosis

- Once personal information is shared it can't be taken back
- Some people experience worry or feelings of stress about sharing information
- Sometimes people can react negatively and this can be difficult
- Telling your school/ college or work can be daunting even though there are laws to protect our confidentiality

It can be a relief to share with someone you trust

- You may feel more supported and less alone
- You may feel reassured with the positive experiences of sharing your diagnosis
- You can share responsibility of transmission with your partner
- There is no risk of prosecution

Some top tips

It is important to remember that you have the right to decide who knows about your HIV, as it is your private information.

Young people have said that close friends and family members who know they live with HIV still treat them the same and can provide emotional relief and support when needed.

If you decide to tell someone about your HIV you will need to plan it carefully. Think about what you might say to questions they may have and be prepared for different reactions.

Did you know?

To prepare for a conversation, it can help to think about how you felt when you were told you were living with HIV and the different questions you had.

Did you know?

You can practice having a conversation about sharing information about a member of your clinic team.

Did you know?

Your employer usually won't need to know your status. However, you could choose to tell them if you feel it would benefit you.

What jobs can I do?

There are thousands of job options and almost all of these are open to you. Like anybody else, the biggest challenge for you will be getting the qualifications, skills and experience you need.

Sometimes people with certain health conditions such as asthma, diabetes or HIV are prevented from doing certain jobs, for example, the Armed Forces (Army, Navy and Air Force). Recent changes means that you can work in the medical profession as a doctor, nurse, midwife etc. as long as you look after yourself and maintain an undetectable viral load if undertaking invasive procedures.

Do employers need to know my diagnosis?

In most cases the answer to this question is no. You won't have to tell them but you may choose to tell them.

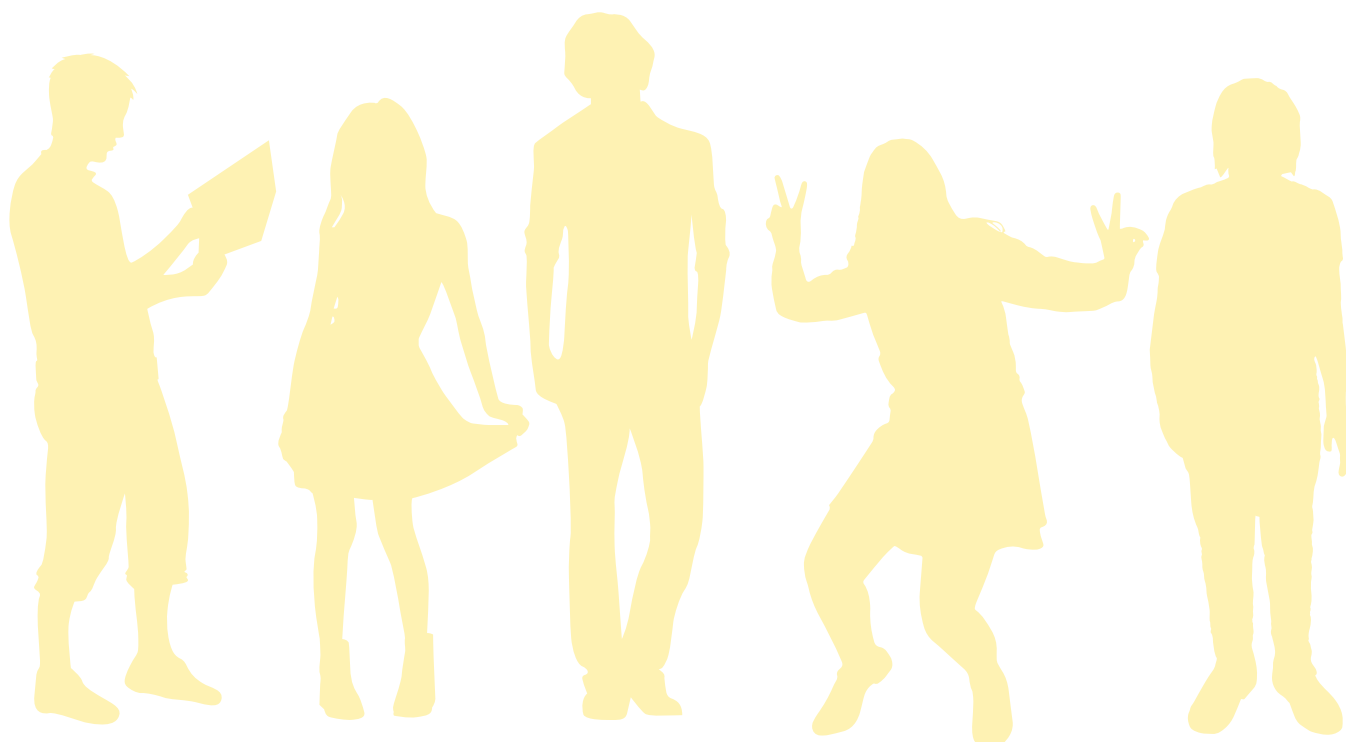
The law says that:

- Employers must keep your personal information private
- Employers cannot discriminate against you because of your status

The Equality Act 2010 protects everybody from discrimination due to things like age, race, sex or disability. HIV is covered within this act.

Some top tips

- It's your choice who you tell
- Plan what you will say first
- Sharing information can be a positive experience



Can I go on school trips, sleepovers & parties?

Of course you can! An important part of your life is joining in with a range of different activities, including travel, trips and social events.

It can sometimes be difficult to remember to take your medicines when you're not in your usual routine or when you are among people who do not know about your medicines.

Here are some top tips:

- Plan what you might say if people ask you about your medicines.
- If your school knows you are living with HIV discuss your medicines with the member of staff you know and trust.
- If your school does not know you may decide it is time to tell them and you can read more about this on the page titled '*How do I talk to people about living with HIV?*'. You can also always talk to your clinic team.
- It is a good idea to have a trusted adult who can remind you to take your medicine and have somewhere to store it safely.
- If you decide not to tell and you are able to manage your own medicines, the clinic team can offer suggestions about the best way of doing this.
- A text message from your parent/family member or alarm on your phone can help remind you about taking your medicine while you're away.
- Remember to plan it all in plenty of time, it helps to be organised. Please get in touch with your clinic team if your medicines are running low.
- See CHIVA website for more information (<https://www.chiva.org.uk/youth/school-and-college/>)



Image by C.C



Did you know?

You can use an unmarked pill box or container in your toiletry bag.

Did you know?

It is okay to say that your medicines are a daily vitamin tablet that lots of people need to take.

What is a healthy lifestyle?

We all have to think about our physical and our emotional health. Here are some top tips and ideas about how you can look after yourself.

Exercise

We all need to exercise. The National Health Service (NHS) suggests we should try to exercise every day for 30 minutes or more. This can include having a fast walk, going for a jog, a swim, dancing, karate, bike riding, playing football, the list is endless! Basically, anything that gets you working hard enough to raise your heart rate and break a sweat.

Doing this is excellent for:

- Improving heart function
- Maintaining a healthy weight
- Improving bone health

What activities do you enjoy?

How might you ensure you get the recommended weekly exercise?



Image by B.N

Diet

Being mindful of what we choose to eat and drink can have an impact on our weight, health, energy levels, concentration and mood. The Eatwell Guide on the next page is a useful tool to check that you are eating a balanced diet.

- **Fruit and vegetables:** Which 5 portions of fruits and vegetables do you enjoy?
- **Proteins:** How would you include some protein in your diet?
- **Dairy:** Do you include dairy in your diet?
- **Carbohydrates:** Do you get enough variety of carbohydrates?
- **Water:** Do you drink enough water?
- Do you ever check your food labels for fat, salt and sugar content?

Did you know?

Exercise can also help to improve your self confidence and allow you to develop new social skills.

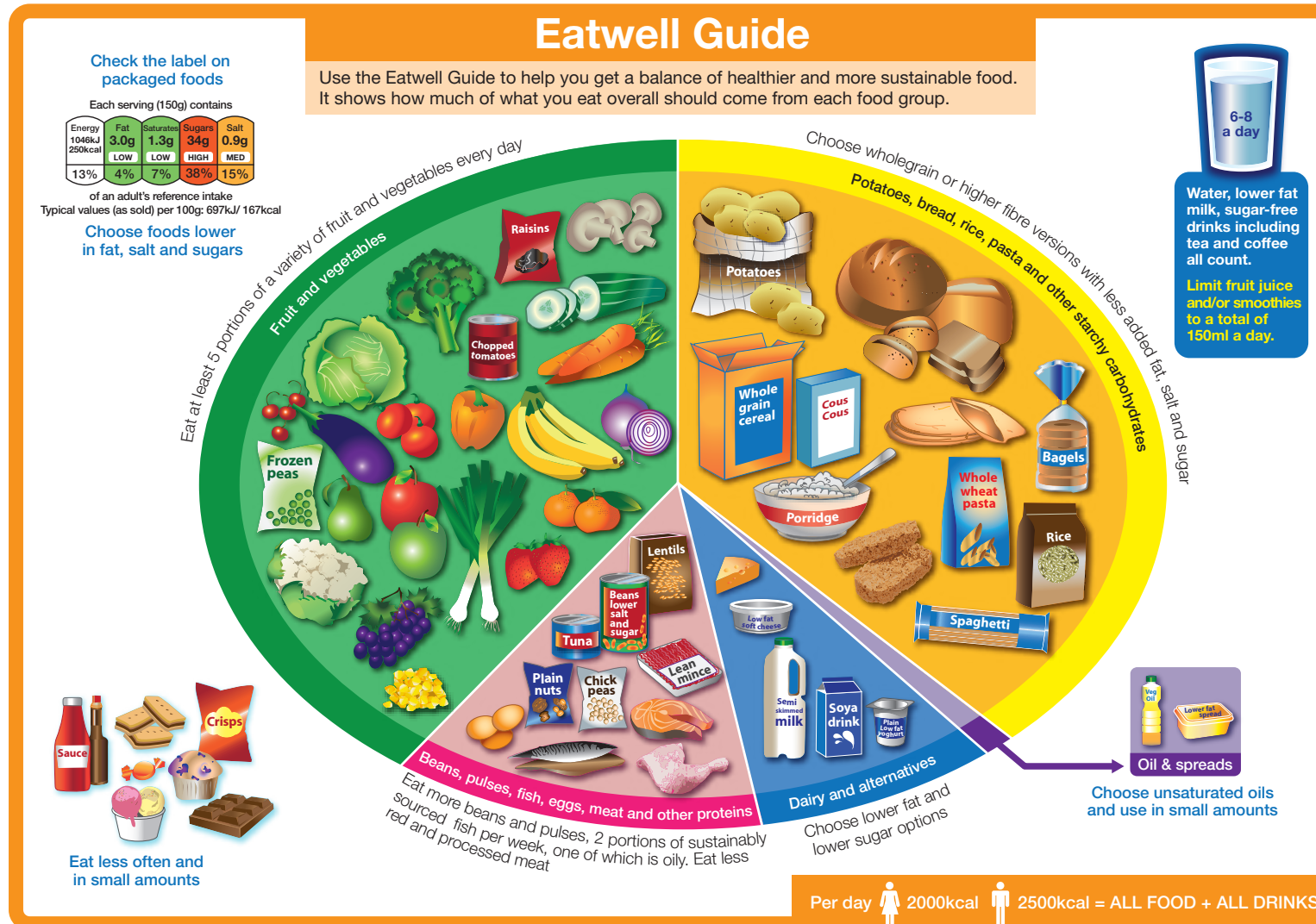
Did you know?

Scientists have discovered that exercise makes your brain release chemicals that make you feel good!

Did you know?

Calcium is important for growing bones and teeth. To absorb calcium from our diets we need vitamin D. The majority of vitamin D in our bodies comes from sunlight. Vitamin D levels frequently drop particularly during winter months. Your clinic team can provide a practical guide on increasing your calcium/vitamin D.

All about me



Source: Public Health England in association with the Welsh government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

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Alcohol and Drugs

We know that misusing alcohol and drugs can poison the human body and affect our physical and emotional health. We would encourage you to talk openly with your clinic team about any experiences with alcohol and drugs, as these may cause interactions with your medicines. Also, this allows us to support you. Here's what some young people said about alcohol and drugs...

"When you are under the influence of drugs and/or alcohol, you are very vulnerable"

"Personal problems can't be fixed with drugs and/or alcohol"

"If friends are drinking and using drugs and you don't want to join in you can say no"

"It is important to talk to people you can trust about any pressures to drink or try drugs"



Did you know?

You can speak to your clinic team in confidence if you are concerned about alcohol and / or drugs affecting you or your family/ friends.

Emotional well-being

We all have difficult thoughts and feelings from time to time and it can be a really unsettling and isolating experience. We know that talking to a person you can trust can be really helpful, here are some ideas why:



Have you ever had any of these thoughts?

.....

How would you recognise when you are struggling?

.....

What might stop you seeking support?

.....

Do you have any experiences of talking to someone you trust? How did it go?

.....

Top tips for emotional wellbeing

It is usually best if you can talk to someone you trust about how you feel. However, it is not always easy to start conversations and there are lots of other things that may help you with your thoughts and feelings, here are some top tips:

- Express yourself through art and creativity
- Play sport, dance, exercise - anything that makes you feel good
- Write your thoughts and feelings down
- Make time to relax and unwind
- Remember the things you are great at, all those talents, skills and qualities.

Where can I get help?

Clinic Team

Some services have access to Psychologists, who are there to listen and assist you with your physical and emotional health. Your clinic team will be able to guide you in finding a professional to help you. You can also talk to your GP about local support services.

School / College

If you feel able, you can talk to staff, such as a mentor, head of year or school counsellor.

Where else can I get help?

Childline

0800 1111 - A free, confidential phone line for young people, where trained counsellors are available to support you anytime day or night. You can also contact and chat to a counsellor online via <https://www.childline.org.uk>

Samaritans

116 123 - A free, confidential, phone line for adults open 24 hours a day, 365 days a year. You can also email jo@samaritans.org

Did you know?

It is very common to experience emotional difficulties. It is estimated that 1 in 4 people living in the UK have or are experiencing mental health problems.

Did you know?

We know that our emotional health is as important as our physical health.



Travel

Travelling can be an exciting adventure, which allows you to gain new experiences. When planning a trip abroad, there are a few things to consider that will help you enjoy your trip and stay safe.



Image by F.K

Can I work abroad?

Yes you can! People living with HIV can live and work in most countries. Lots of countries have no restrictions, however, there are a few small exceptions.

For up to date information on travelling, living or working abroad please see www.namlife.org or contact THT Direct on 0808 802 1221 (Free).

For travel health advice including travel vaccines visit:

- www.chiva.org.uk/guidelines/travel-children-and-adolescents/
- www.fitfortravel.nhs.uk
- www.hivrestrictions.org



Image by V.M

Groups and Peer Support

Meeting other young people living with HIV

At first it may seem daunting to think about meeting other young people living with HIV or joining a support group. This is understandable and it is normal to feel apprehensive meeting others and trying something new. However, like lots of things, once you make that first step it can open up lots of opportunity to meet others, talk about living with HIV openly in a safe and confidential environment, try new experiences, gain new skills and importantly, have fun!

Here are some quotes from young people who attend one support group in Leeds called 'Together 4 Life'

"The reason why I started the group was to make friends. At first I was scared and shy but when I got there they were really friendly and nice and everyone welcomed me."

"If you are part of the group you are part of a big family, they are always there for you. Skyline made me grow up and start thinking about my health."

"The group has really given me support. They have made a confident bright person I am today. They have been there through good and bad times. I really enjoy going to the group. I have developed a lot more knowledge than before."

"During the group I have made new friends that I know will be there for a long time. They have made me feel comfortable. I am able to trust the people within the group and I know I can trust them with my heart. I can now walk with my head held high."

Ask your clinic team about HIV support groups in your area.

As well as local services, there is a national organisation, CHIVA, who provide lots of helpful information and support for young people living with HIV. In 2010 CHIVA set up 'Freedom To Be' a yearly support camp for HIV positive young people. At camp, you are able to join in creative workshops, try exciting outdoor activities and express yourself, whilst having fun and building friendships.

"As long as I try I can do anything" (Young person after attending CHIVA camp 2017)

What young people attending clinic in Leeds have to say about transition

“It’s another step towards a long journey. Just know you are not alone and there are others in your position.”

Written by B.S

“Transitioning is like moving forward. Think of it as a journey, just like when you have to move from year 7 to year 8 in school. At first it will all seem scary but remember you are definitely not alone.”

Written by T.D

“You are not alone. There is always someone to talk to.”

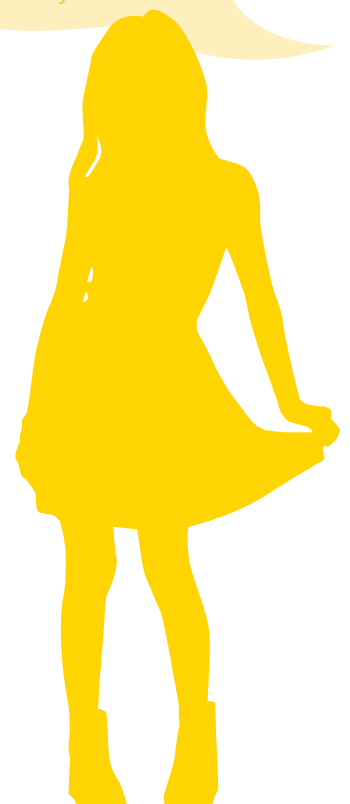
Written by N.S

“There is always someone to talk to, you are not alone. You will always feel welcome and there is support for you anytime of the day.”

Written by B.S

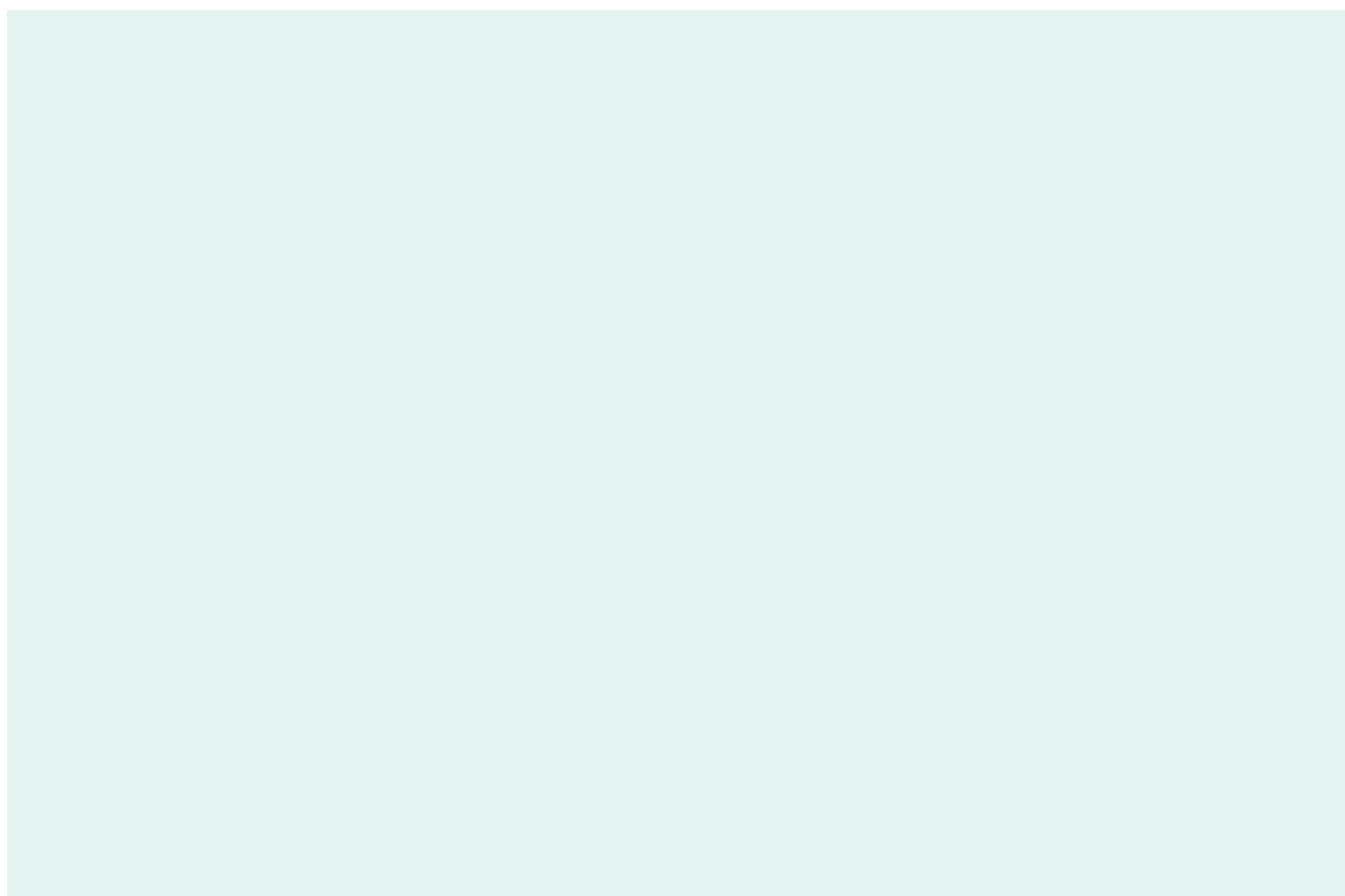
“Personally, I treat the transition as if it was like moving from primary to High school. There isn’t much difference other than the maturity that is required for a successful transition.”

Written by N.S



Welcome to your adult clinic!

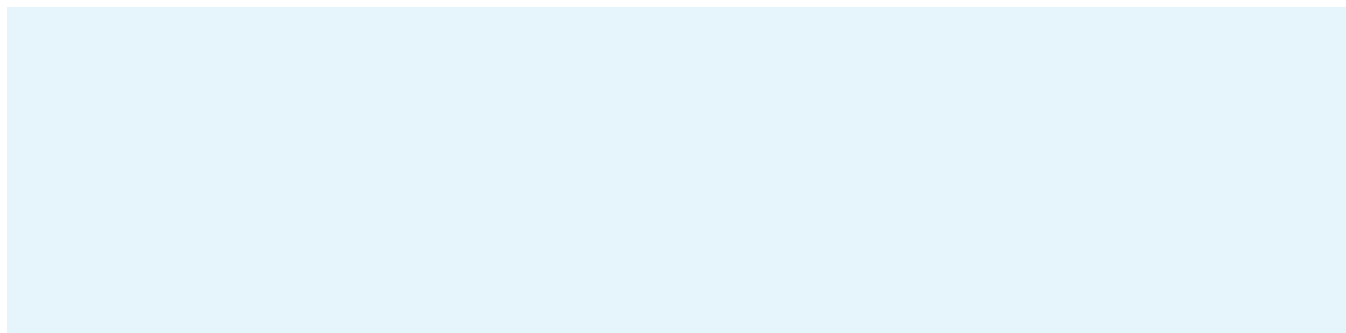
Use the space below to write any questions you would like to ask about moving to the adult team...



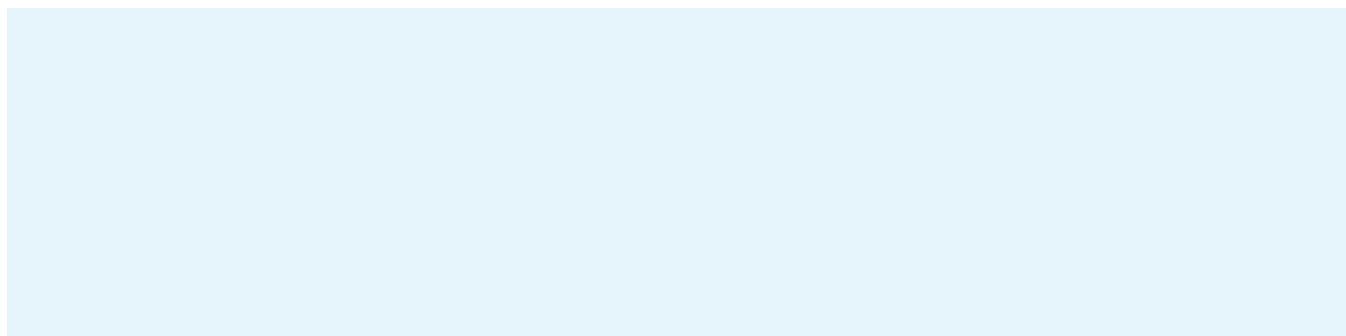
When you and your clinic team feel you are ready, you can move on to your adult clinic. Talk to your clinic team about having a look around beforehand so that you are familiar with how to get there, the reception area, waiting area and clinic rooms. If you haven't already done so, you can also start to get to know the team.

Useful Resources

Your Local HIV Services



Your Local Voluntary Sector - Support Services



Websites for advice, support and information

Website	Information
www.chiva.org.uk	The Children's HIV Association
www.bodyandsoulcharity.org	HIV information and peer support for young people
www.NCB.org.uk/LifeLinks	National Children's Bureau
www.tht.org.uk	Terrance Higgins Trust HIV Organisation
www.themarketplaceleeds.org	Sexual health support and advice
www.avert.org	HIV Education
www.i-base.info	HIV information
www.teenagehealthfreak.org	General sexual health information
www.thinkyouknow.org.uk	Support & advice in reporting online abuse

Aidsmap

- www.aidsmap.com/e-atlas - a searchable database of organisations working in HIV around the world
- www.aidsmap.com/resources - a link to the full range of NAM's online resources covering all aspects of living with HIV
- www.aidsmap.com/hiv-test-finder - use the HIV test finder to locate a HIV testing centre convenient to you (UK only)
- www.aidsmap.com/translations - NAM has translated versions of a huge range of our patient resources
- www.hivrestrictions.org - this website hosts a global database of HIV specific travel and residence for restrictions for people living with HIV

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- CHIVA and additional charities and organisations who support young people to live well with HIV

Contact details

We would love to receive any comments/feedback in relation to the pack.
Please send to:

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