

Great Ormond Street Hospital

'S

# TRANSITION

WORKBOOK

# INTRODUCTION

If you are reading this, you are probably a patient at Great Ormond Street Hospital (GOSH). As you know, GOSH is a children's hospital; some patients come here when they're babies, others come here when they're older but if you need ongoing medical care or support you might be a patient at GOSH throughout your childhood.

Because GOSH is a hospital for children and young people, as you become an adult and gain more independence we have to say goodbye to you so you can go on to adolescent or adult services.

When the time comes we want you to feel informed about and equipped to leave GOSH. You might be excited about it because you'll be more independent and looking forward to meeting new people, or you might be worried about it because you will be leaving the people and environment you have grown up with, or you could be both! However you feel, we need to prepare you as best we can to transfer from GOSH to your new hospital or hospitals so it can be a positive experience. We call this preparation transition.

We made this workbook because we want you to be fully involved and engaged in your transition as this will ensure that it's as smooth as possible. You might never have heard of transition before now, but don't worry, this workbook will help you through it.

# A NOTE FROM YPF

Now you know what transition is we want to explain a few important things about it!

You probably won't leave GOSH until you are 16–18 years old but your nurses and doctors will start discussing transition with you as early as the age of 12 to ensure you feel fully informed and prepared to move when the time comes.

Transition may sound scary, especially if you have been a patient at GOSH since you were young but it is a really positive thing. Transition gives you all the skills you need to feel ready to take responsibility for your condition and communicate independently with your healthcare team, rather than through your parents. This will give you a lot of independence too!

The Young People's Forum (YPF) created this booklet with HATO and GOSH Arts during a number of workshops to help make transition easier for you. Some YPF members are currently going through transition and have shared their thoughts and feelings as well as top tips about transition in this workbook. We really hope that you will find all the advice and the suggested activities helpful.

*Good Luck with your 'transition journey'!*

Grace, Chair YPF

HATO x YPF

# HOW WE MADE THIS WORKBOOK

HATO chatted to young people in the hospital to find out what they already knew about transition. Based on their answers they asked five young people going through transition and five young people who had transferred to adult services to do lots of different, fun exercises about their experiences.

HATO then met with us,  
we designed

## THIS FONT

chatted about what we did and didn't know about transition and created shapes to demonstrate our positive and negative feelings about it. Some of us feared leaving our doctors and nurses, this is the shape we made



But then other patients said that it wasn't all bad, that we could look forward to more independence and they supported our fear by drawing this



Finally, HATO asked clinical staff to share their top tips about transition and how they support young people during this time.

We wanted to share all these thoughts and feelings with you to show you that transition doesn't have to be lonely or scary, it can be a positive thing if you take control of it!

YPF  
2018/9

# HOW TO USE THIS BOOKLET

This workbook is a place where you can keep key information, get reassurance and advice, write about how you feel and list all the questions you have during and after your transition.

## **Keep your most important information here**

Use this workbook as a safe place to record everything you will need to remember during or after your transition. You could use it to take notes before you transfer to your new service to remind you of who you can talk to about transition or take it to appointments at your new hospital so your new care team can use it as a shorthand to understand your medical history and how you are feeling.

## **Know you're not alone**

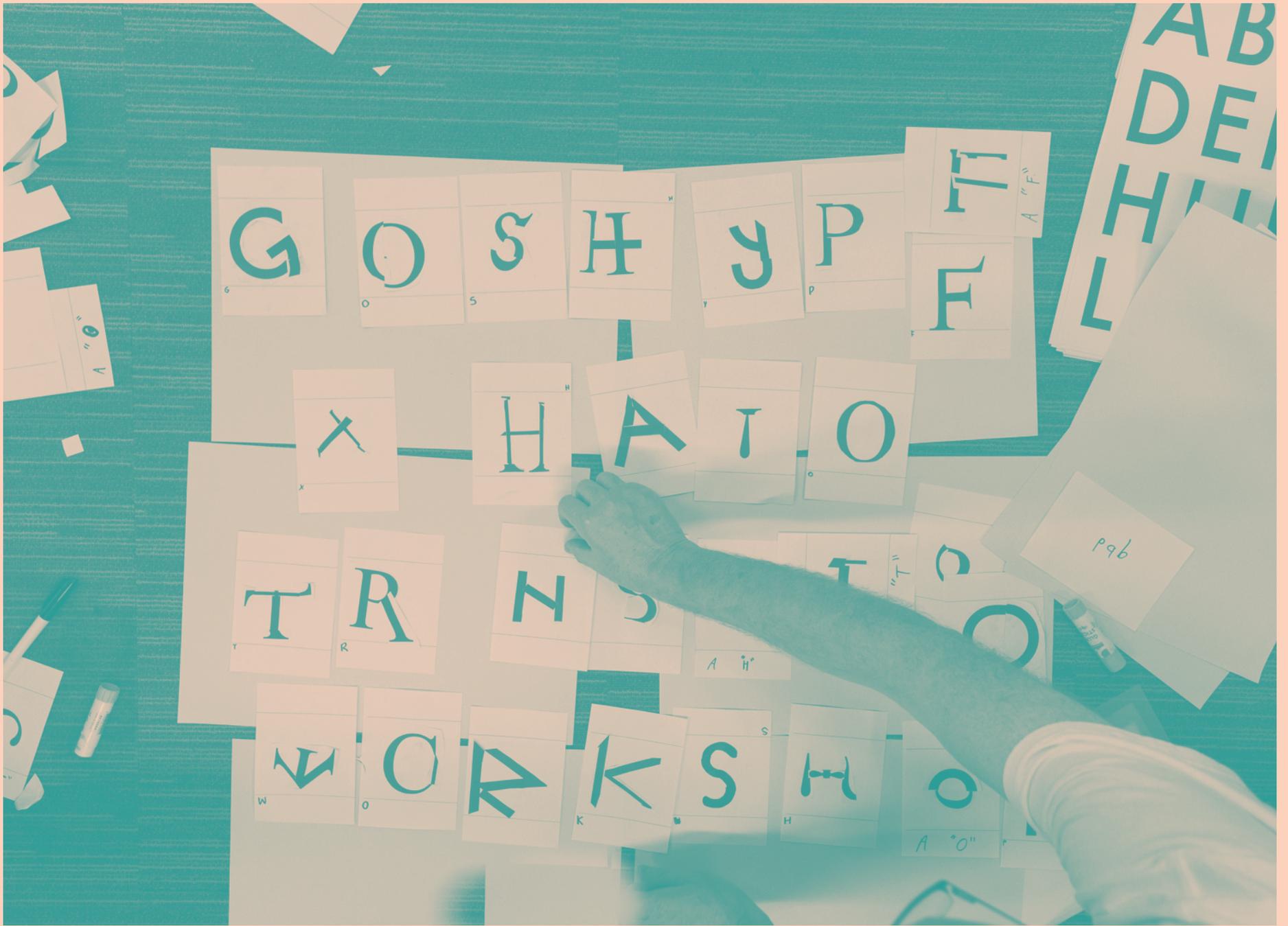
Whenever you feel worried about transition, don't forget that there are people all around you at GOSH who probably feel similar to you. There are shapes throughout the workbook that represent lots of different thoughts the YPF have about transition, they might help you turn your negative thoughts in to good ones!

## **Look at the tips from other patients and staff**

Transition might feel a bit overwhelming, but again, you're not alone! In the middle of the workbook we've included some tips from previous GOSH patients and experts who have been helping patients through transition at GOSH for years.

## **Write and draw how you feel**

There are some thought pages in the workbook you can use to write down what you are excited or worried about. Why not try a 'free writing' exercise to help you reflect on and process your feelings. Some pages in the workbook suggest you draw shapes which reflect your positive or negative feelings about transition like the YPF have done.



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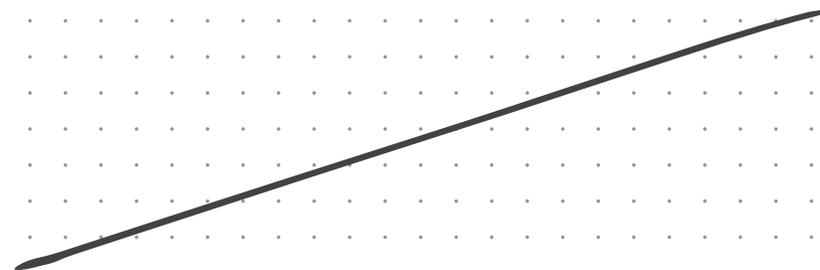
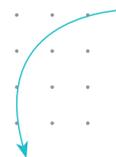
I fear leaving my doctors and nurses

I am looking forward to more independence

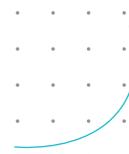
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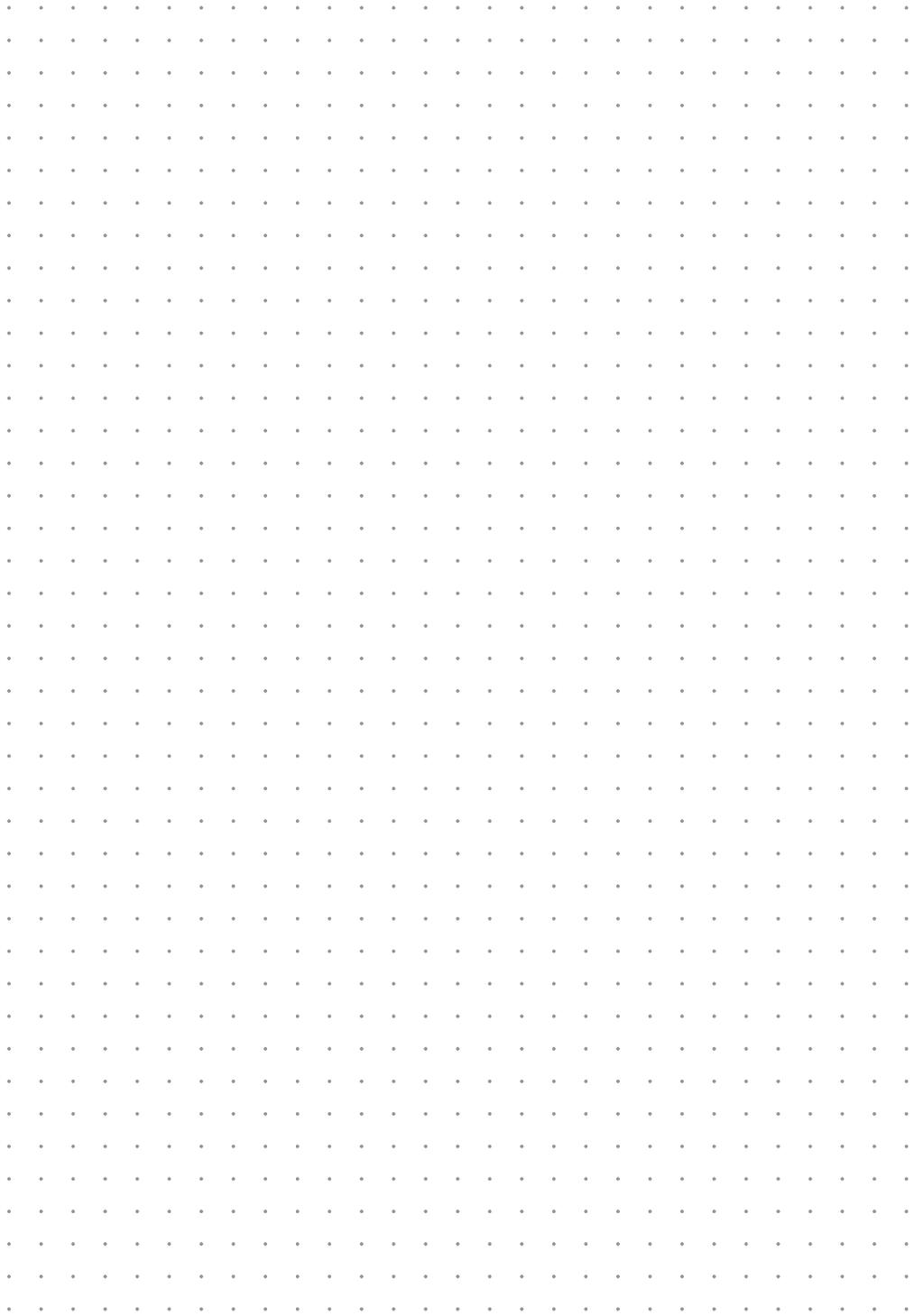
Record your emotions through shape

Positive shape



Negative shape





I feel alone and scared about the future

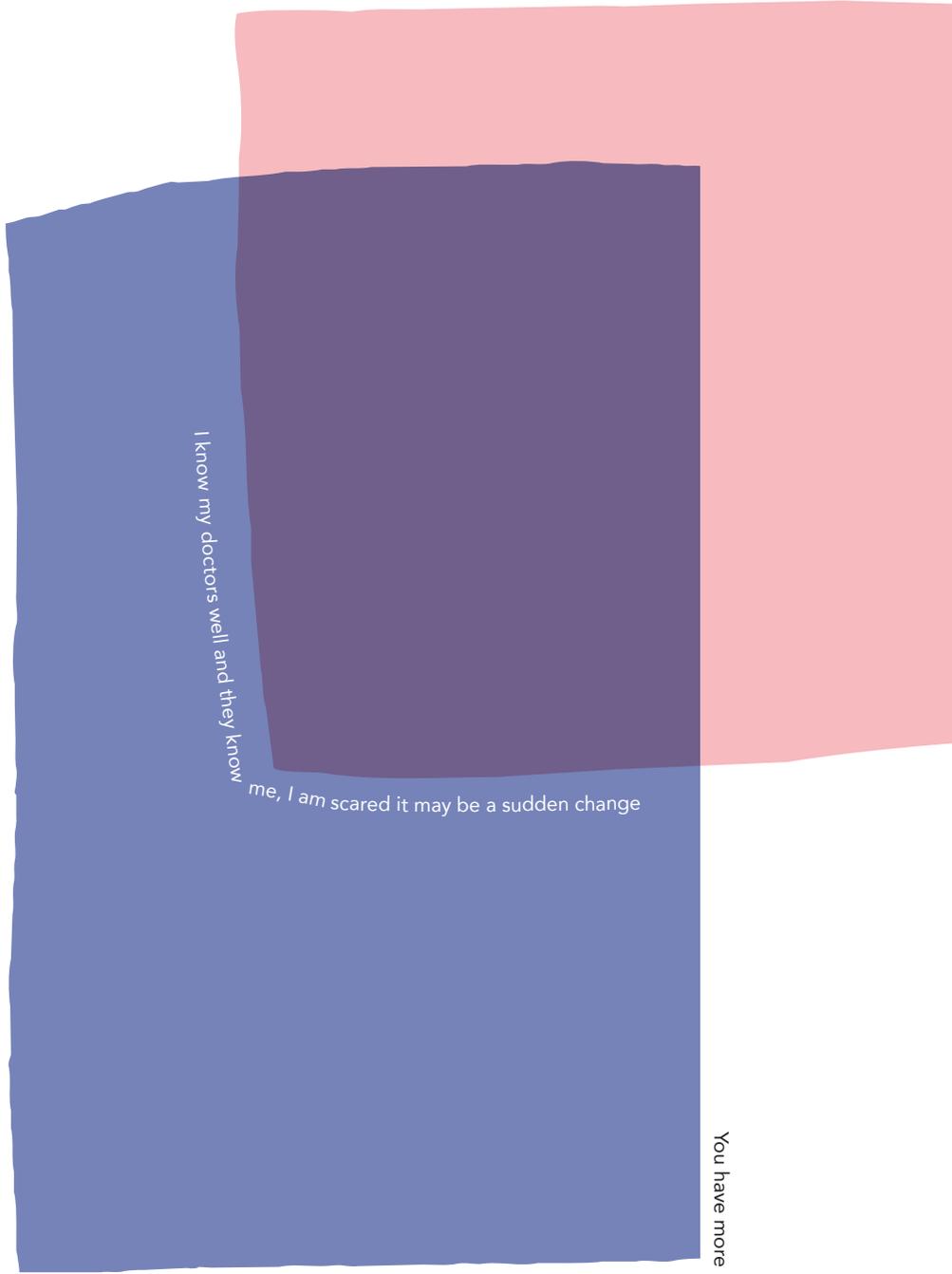
You are not alone transitioning | like stars in the sky

independence and are treated more like an adult

You have more

I know my doctors well and they know

me, I am scared it may be a sudden change







Date:

Record your emotions through shape

Positive shapes



# RECOMMENDATIONS

from  
the **TEAM AT GOSH**

## **Nurses are always here for you**

Nurses have a lot of experience of supporting people through transition as we have supported many people to transfer in the past. Our aim is to always help solve whatever problems you have, so don't feel shy to tell us what you are worried about. When a patient asks for help we will try to understand their problem, and then suggest small achievable goals which they can work towards. Definitely come and talk to us if you have any fears or you just want to find out more about what to expect when you transfer.

If you find it hard to stick to your goals don't worry, just ask your nurses for tips. For example, if you can't remember the names of your medicines, you could take a photo on your phone and show it to your doctor. If you find it hard to remember to take your medicine, you could try setting an alarm on your phone to remind you. There are always ways around!

## **Writing in your workbook also helps nurses and doctors**

You could use your workbook to record your mood, your sleep, your medication (am/pm) – having this information is actually very helpful because it helps us understand how you've been feeling at a glance and we can then advise you better. Feel free to express yourself in the way you want. You can put smiley faces, numbers, letters or other symbols to show how you feel – whatever works for you!

Consultations can be a bit formal and are sometimes not as relaxed as they should be, especially if there are time pressures. It's often easier

to talk about things you've written down isn't it? So don't forget to bring your workbook along with you if you have been using it to record your goals, worries or questions. The doctors and nurses will find it really useful!

## Knowing more about your condition can help you feel more in control

Gaining a better understanding of your condition can help combat the feelings of uncertainty that transition might be creating and can be really empowering. The more knowledge you have about your medication, what to do if you feel unwell etc. the more control you will have over your condition. Nurses and doctors are here to provide this knowledge or help you find it!

Keep an eye on other institutions and charities. There are always different groups that can provide you with more information and guidance not just about the medical side of things, but also the social and emotional impact of your condition as well! For example, if you've got a cardiac condition, there's the British Heart Foundation, or if you have an eating disorder there is BEAT.

## Nurses and doctors will help you gain independence

Throughout transition, you'll gradually be encouraged to take on more responsibility for your care, but remember that it's always ok to ask for help. It's not a strictly linear path where you're suddenly completely independent; there will be times when you'll feel very independent and some other times when your independence will dip a bit, for example when you're going through exams or you're feeling particularly unwell.

You can always rely on us if you find it hard to share how you feel with your parents. If you let us know about it, we are more than happy to facilitate tricky conversations. We can do it together, we can go through it privately to help prepare you to independently talk to them or we can just initiate the conversation and leave you to it!

## Final thoughts

Transitioning to adolescent or adult services can actually be quite exciting as it means you'll be treated as a grown-up and you'll have ownership of your condition.

## Tips from...

### **Emma Ninnis, Clinical Nurse Specialist, Complex Epilepsy**

I came to GOSH in 2002 to train as a children's nurse. I have been looking after young people with Epilepsy since I qualified in 2005. My main role is to support young people with their epilepsy, teaching the importance of putting their health first and helping each person to become as independent as they can be when it comes to their medical care.

### **Nigel Mills, Clinical Nurse Specialist, Adolescent Health**

I'm Nigel and I'm a Clinical Nurse Specialist for adolescent health. I've been at GOSH since 2007 and my role is to advise and support young people and their families in the hospital as well as staff looking after young people in the hospital. I also helped set up the Young People's Forum in 2012.

### **Dr Sarah Aylett, Consultant Paediatric Neurologist**

I'm Sarah and I am a Consultant Neurologist looking after young people with epilepsy and disabilities. I have been involved in writing information for young people and running workshops for young people and their families to help them with transition. I also helped with the Growing Up and Gaining Independence programme.

# TIPS FROM JPF

## Asking questions

### Speak up

Be completely honest with all the people trying to help you.

### Ask questions

Asking as many questions as you can will help you understand more and show doctors you are taking it all seriously.

### Talk to people

Some people find transition scary and it can be quite lonely so tell people how you feel about what's going on. Talk to your friends about the changes and don't isolate yourself.

### Find out as much as you can

Try and find out what your new hospital is like and try to meet your new team. This will help to reduce initial nerves as it won't seem as foreign and as new.

### Seek out the specialist

Specialist nurses still exist in adolescent and adult clinics and can be friendly and reassuring.

## Knowledge, documentation & records

### Learn about your condition

Know what your symptoms are, what helps, what doesn't help. Know what medication you are on, know how your condition is likely to progress. This will help you to have more adult conversations with your doctor.

### Have copies of your medical notes

This will help your new team to understand more about you and your condition and what has been done already.

### Keep a diary

Write down all your appointments so you don't forget them. A diary of symptoms can also be helpful so if you are overwhelmed in appointments you remember what's happened.

### Write things down

Make notes in appointments and write when you feel down.

### Keep records!

A lot of my records from GOSH got lost in transfer so I had to have a lot of tests repeated. Keep hold of any letters with results from tests and so on – they may come in very useful!

## Change, differences & similarities

### Independence is amazing!

You feel like you have more power and more say in your care. My friends sometimes come to my infusions with me to keep me occupied!

### It's OK to be worried

It's scary going into the unknown but it can also be exciting to meet new people and try different things. Remember to keep a support network around you.

### Be patient

It takes a little while for things to be set up and for you to settle which can be frustrating but it will get sorted and if you have any problems with your health go to A&E or speak to your GP. Don't expect everything to happen all at once.

### Adult services aren't that different!

The doctors and nurses are similar to those at GOSH. They still help you with your transition and understand it's new for you. They help you to get used to it!

### There isn't always the same level of explanation

At GOSH, they always explained all of my tests and what was happening really well, but sometimes they don't in adults so ask people to explain stuff if you want them to.

### Same care

I still have yearly check-ups, blood profiling etc. – the same amount

of appointments as at GOSH so don't worry that you won't get the same care.

### Some things stay the same

Appointments still require a lot of waiting time so some things don't change!

### Download, download, download!

There are not bedside entertainment systems or play workers, so at night when you can't sleep an episode of your favourite show will be needed.

### Make sure to ask if there is a games room!

At my hospital there is a games room, it's so much better than the GOSH playrooms, equipped with a pool table, Xbox and loads of other games I'd never even heard of!

### Don't be anxious that doctors don't know all about you.

They are just getting to know you and records are there to help them.

## Support

### Take your comforts to hospital

Even though it's an adult ward, still remember to take your teddy and stuff that makes you feel at home in the ward. The nurses still sometimes play cards with me!

### Make friends!

On teen wards, everyone is on their own and just as bored and awkward as you. Don't be afraid to start a conversation even if by just asking where the kitchen is. It will make

time pass so much more quickly and everyone will thank you. Just remember that everyone is in the same boat!

### **Rely on your close ones**

Have a parent, carer or a friend come with you for the first few tests and / or appointments so that it isn't so daunting. Don't throw yourself into the deep end!

### **The nurses are happy to help**

Parents can't stay with you as there are no beds or parent/family hotels but this can be a good thing! And if you ever want or need anything that your mum would normally do, the nurses are happy to help!

### **Parents are always welcome**

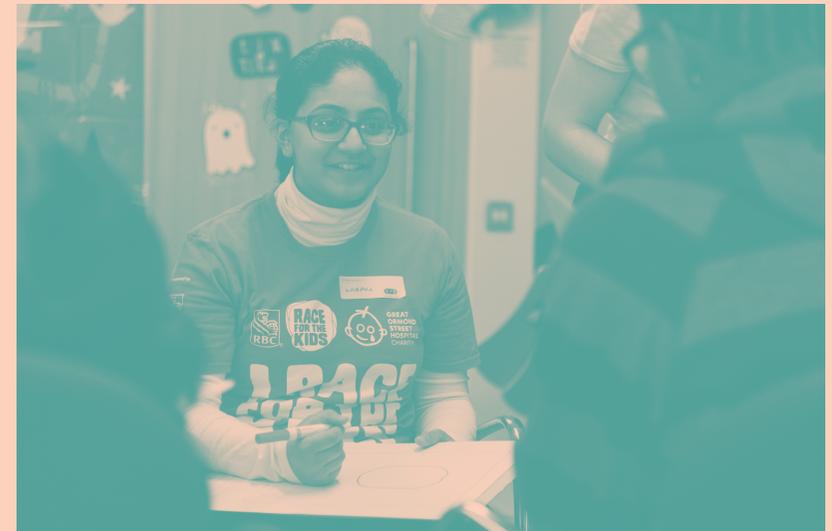
Your parents are still welcome but doctors will talk to you much more than at GOSH which is good!

### **Remember the good stuff**

It's hard having a chronic condition and can be hard to see there are good things. Some of these things can be making friends at the hospital, getting closer to your family and helping raise awareness. It's also important to remember the achievements that you have made despite being ill.

### **Try not to worry!**

Because GOSH used to do my prescriptions, when I came to UCLH, they changed lots of the brands of my medication but it's all still the same stuff! Don't worry about it.





Photos from GOSH Transition workshops with  
GOSH Young People's Forum 2018-19 & HATO

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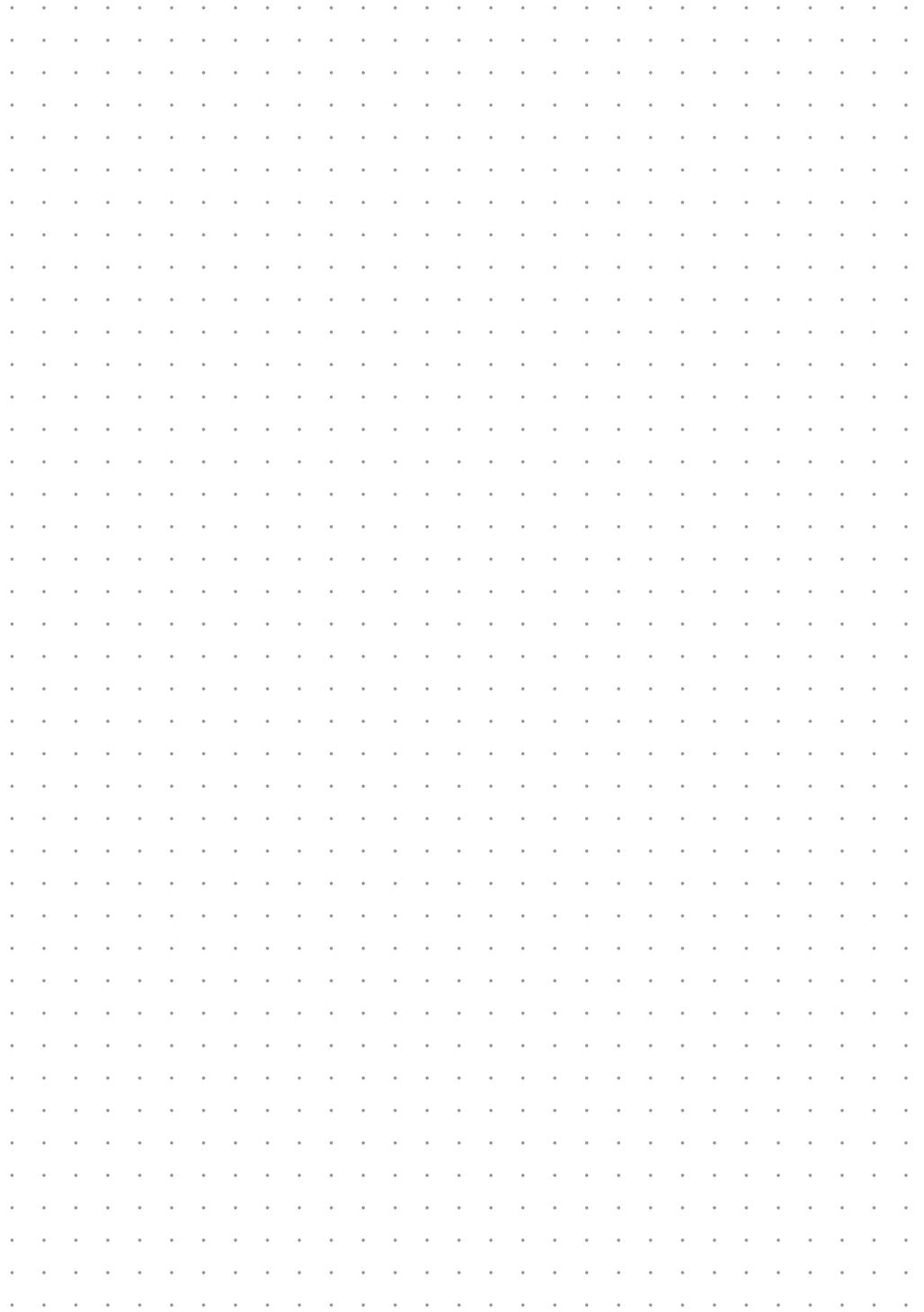
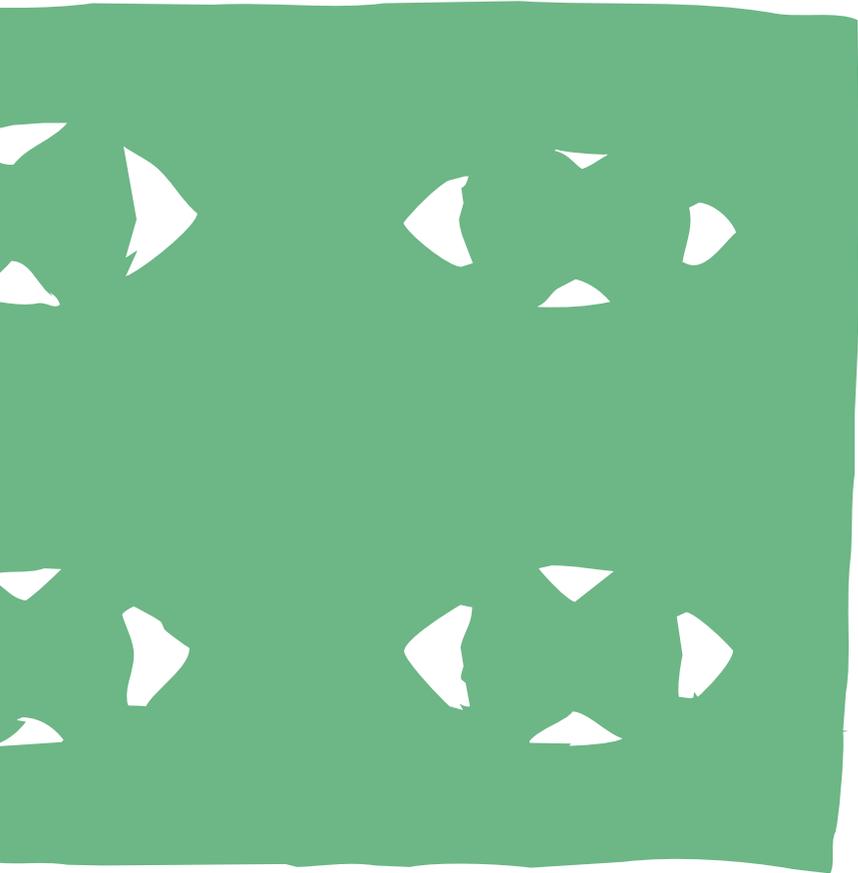
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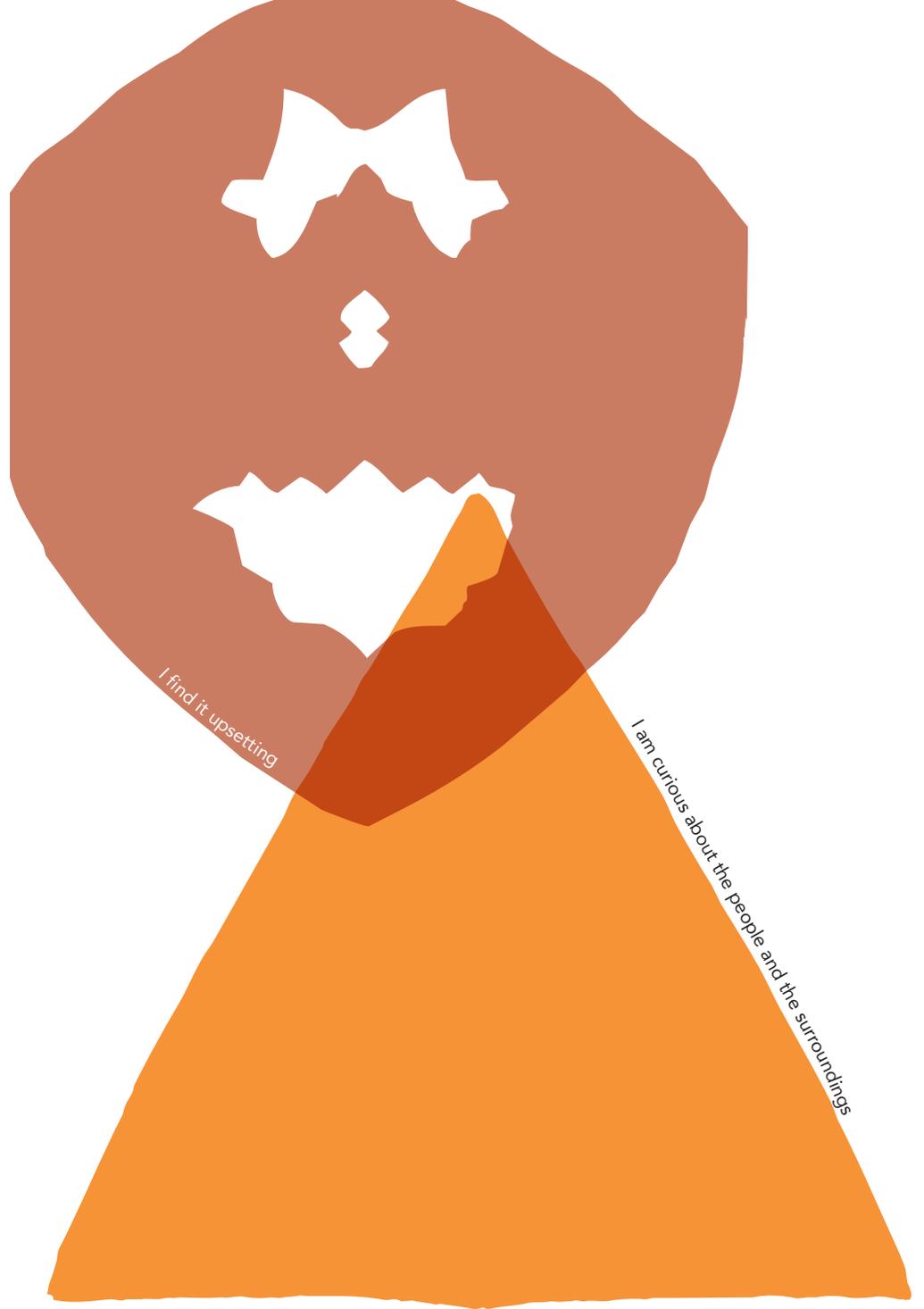
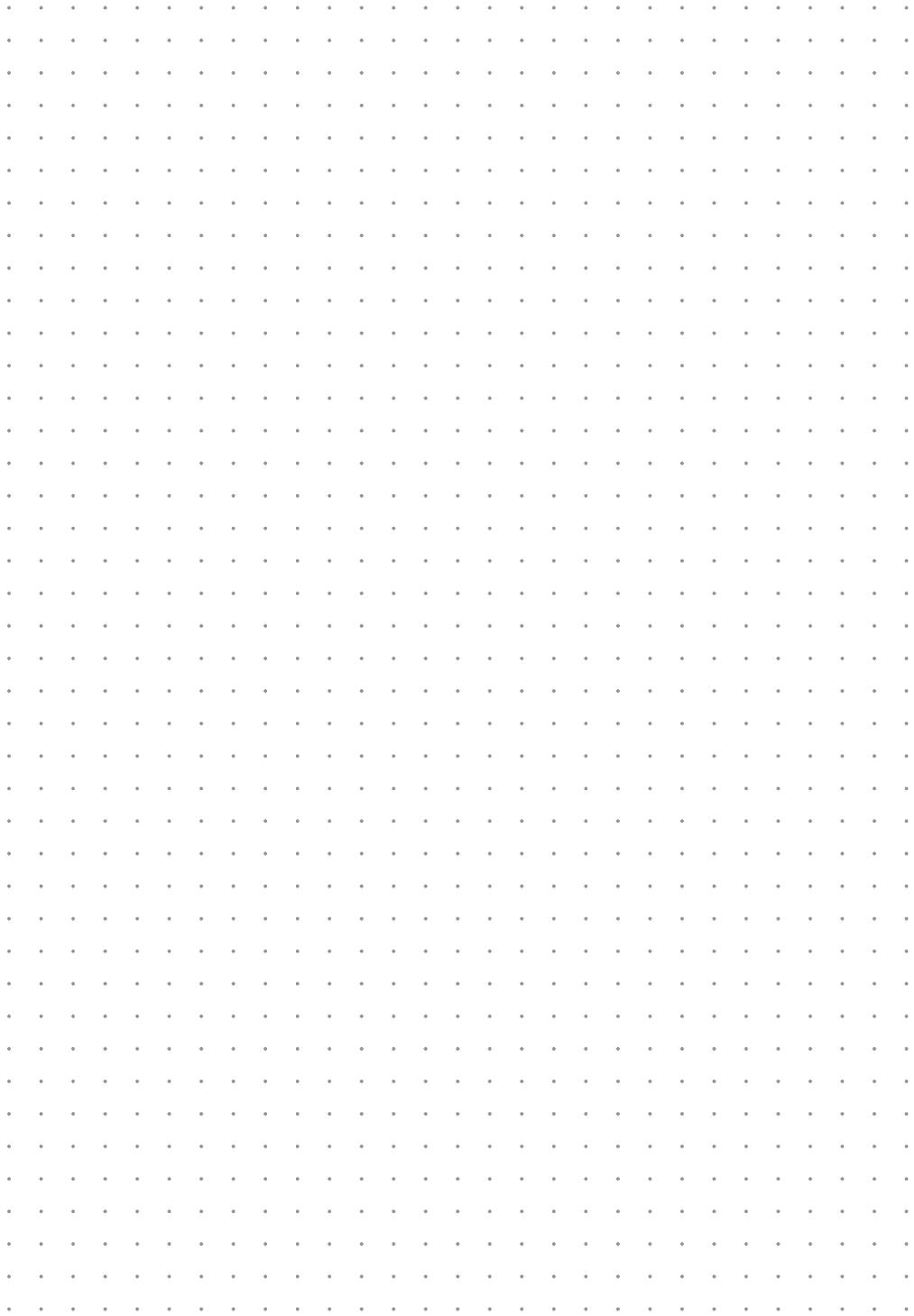
Positive shapes



I don't want it to happen

Transitioning will be fun and new

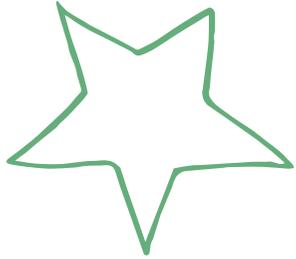
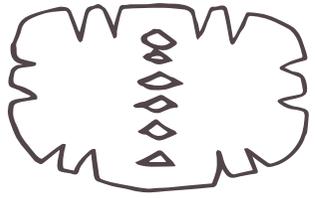




*I find it upsetting*

*I am curious about the people and the surroundings*

Date:



Record your emotions through shape









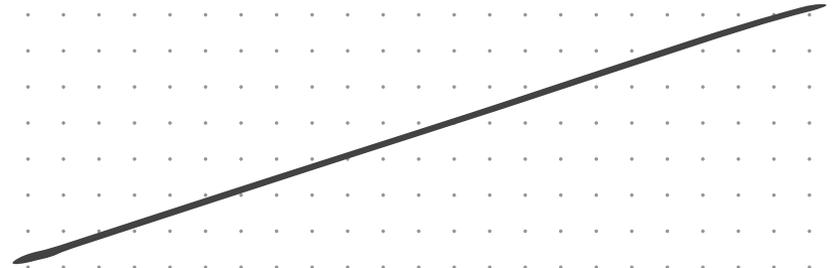
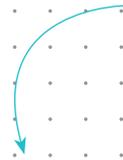
You don't know where it is going to lead to

Just like waves there are peaks and troughs in transitioning

Date:

Record your emotions through shape

Positive shape



Negative shape



# PATIENT INFORMATION

My name \_\_\_\_\_

My date of birth \_\_\_\_\_

My mobile number \_\_\_\_\_

My email \_\_\_\_\_

Age I'll transfer from GOSH \_\_\_\_\_

Medication \_\_\_\_\_

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Specialities \_\_\_\_\_

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## People I can contact

Doctor(s) \_\_\_\_\_

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Clinical nurse specialist(s) \_\_\_\_\_

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Other healthcare professionals \_\_\_\_\_

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# AFTER GOSH

If you don't know yet when you are going to transfer from GOSH and which hospital you are going to transfer to, ask your nurses or doctors about it.

Hospital name(s) \_\_\_\_\_

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Hospital address(es) \_\_\_\_\_

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**People I can contact**

**Doctor(s)** \_\_\_\_\_

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**Nurse(s)** \_\_\_\_\_

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**Other healthcare professionals** \_\_\_\_\_

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