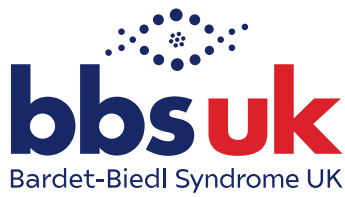


My Life, My Future!

A young person's guide to
living their life with
Bardet-Biedl Syndrome





SUPPORTED BY



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Introduction

Some young people say that living with Bardet-Biedl Syndrome (BBS) is like a rollercoaster, with lots of twists and turns; sometimes life feels busy and exciting but at other times it feels like BBS gets in the way and stops them living the life they would like.

My Life, My Future has been put together by Bardet-Biedl Syndrome UK (BBS UK), to help young people who have BBS achieve the best life possible. You may have heard the word 'Transition' being used by health professionals. It is often used as a way to describe growing up and managing changes at key points in our lives. This includes all sorts of things like changing schools, starting work, making new friends or managing emotions. It also includes planning and preparing for your eventual transfer to adult healthcare services. As you get older you will want to have more choice, make your own decisions and develop the confidence to speak up for yourself. My Life, My Future is a useful toolkit of information to help you on your way to being more independent and get you thinking about how you would like to live your life.



When I was 16 I went to the West of England College in Exeter. At the college I learnt how to be independent... I also completed courses in further education including an NVQ in administration. I also did work experience placements. I feel that I have achieved a lot in my life and look forward to enjoying life to the full.





Young people who have a condition very similar to BBS called Alstrom Syndrome came up with ideas to help healthcare staff and other people in their lives understand what was important to them. They chose the name T-KASH, which stands for Transition: Knowledge and Skills in Healthcare. These ideas are represented by 10 symbols which you will find throughout this booklet, along with top tips, thoughts and comments from other young people who are living with BBS, their family members and healthcare staff.



My Life, My Family

As you live with BBS every day it is very important to develop your knowledge and skills regarding BBS and your healthcare which will help you to grow in confidence and start making your own decisions. To do this you will need support from those around you including parents/carers, family, friends, teachers and many other people who know you. Being treated as an individual, developing your personality and having your own identity are very important parts of growing up.

Spending time with family and friends doing things we love is important for our happiness and wellbeing and trying new activities and challenging ourselves helps us to grow in confidence. Some young people who have BBS may find some tasks and activities difficult, and some things may seem impossible, but with support, adaptations, determination and patience, there really are very few limits to what can be achieved. Have a think about what you like to do, what you are good at and what you would like to try but have never tried before. Then think about what you may need help with. Talk to your family about trying something new and ask for support in making it happen. Perhaps set yourself a challenge to learn a new skill or try a new sport.

Some young people may need help with things like washing or bathing, with finding suitable clothes to wear or with fastening buttons or shoelaces and that's ok; being independent also means being able to ask for help when you need it. Contributing to household chores is a good way of showing your family that you are growing up and becoming independent, so if you aren't already helping out around the home, ask for support in identifying tasks that you can do, for example, drying up or emptying the dishwasher, feeding the family pet, laying the table for dinner, watering the garden in summer – you will find there is a lot you can do and you may enjoy it!



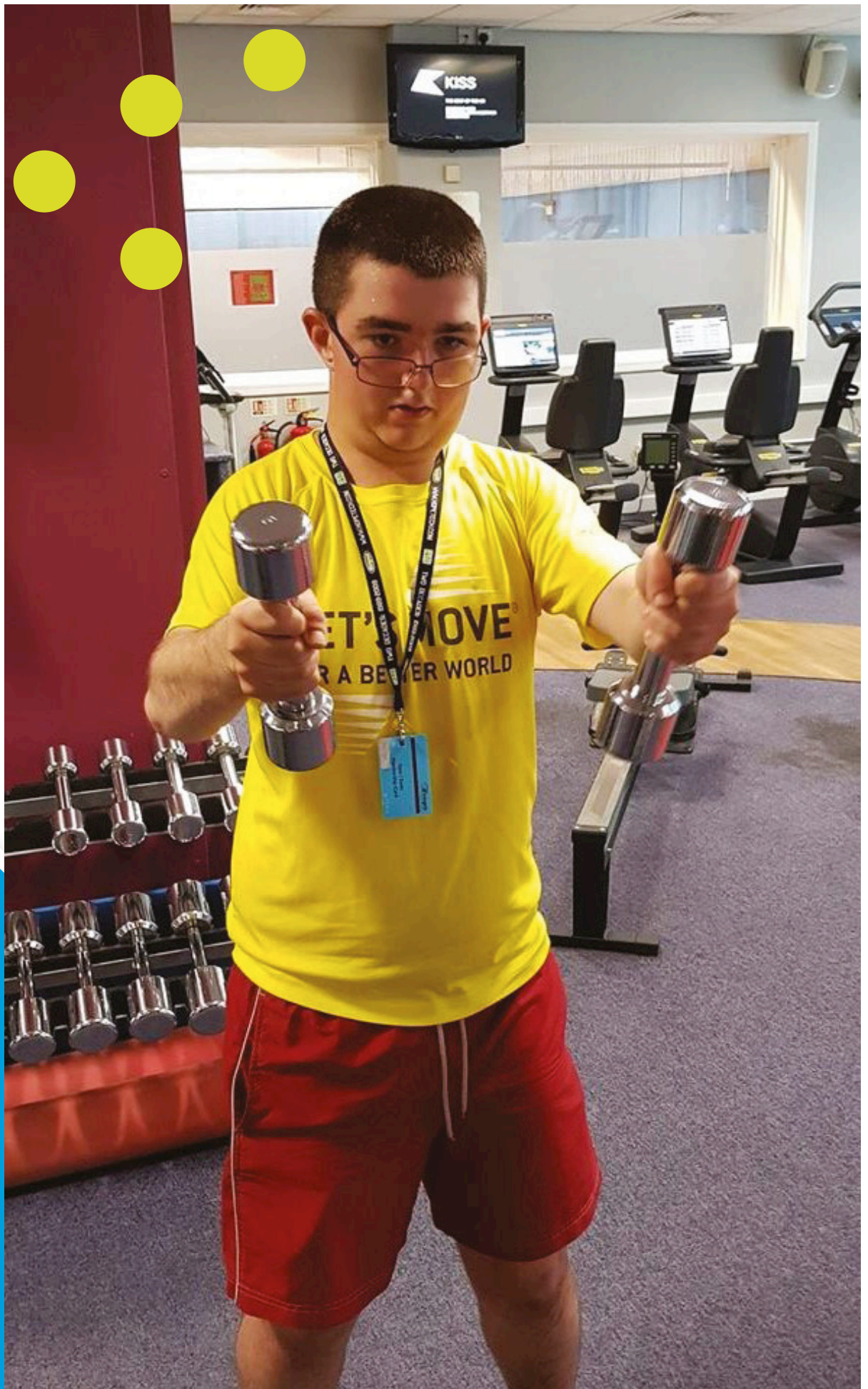
I enjoy cooking, life skills, art, music, friendly people and having a quiet calm room to go to...

What I like to do: _____

What I am good at: _____

New activities to try: _____

Help I might need: _____



Knowing about my Medical Condition




Developing your knowledge about BBS is the first step towards having more control over your health and wellbeing. Young people who have BBS may have some of these symptoms and may have others not listed here. It is important to remember that everyone with BBS is different and will be affected in different ways.

Visual Impairment: You may have an eye condition called Rod-Cone Dystrophy. This means that you may experience difficulties with your vision which may be worse at night and get worse as you get older. You may see a specialist eye doctor called an ophthalmologist.

Obesity: You may have to work really hard to keep to a healthy weight and may see a dietitian who can support you with following a healthy lifestyle.

Learning difficulties: You may need extra help at school or college. You may have an Individual Education Plan or an Education, Health and Care Plan that describes any extra support and resources that you need.



Emotional difficulties: You may find it hard to manage your emotions sometimes and may struggle with anxiety and low mood. You may see a counsellor or clinical psychologist who can help with this.

Developmental delay: It may have taken you longer to reach milestones such as walking, talking, reading and writing.

Kidney issues: The doctors may keep an eye on your kidney function and you may follow a special diet. You may see a kidney doctor called a nephrologist.

Extra fingers and/or toes: You may have extra fingers or toes or have had them removed when you were little.

If you are worried about any of the above information, talk to a parent/carer or trusted adult. If you have an appointment coming up at a BBS clinic, write your questions down to discuss with your healthcare team; it is important that you don't 'bottle up' any worries.



A counsellor can help you talk about BBS and your emotions and identify what you are worried about.

Your Questions: _____



Your Questions: _____



Speaking Up For Myself



You may attend lots of medical appointments including a specialist BBS clinic to make sure that you are as healthy as possible. You are entitled to excellent healthcare that is centred on you and that is right for your age and development. It is important that healthcare staff are knowledgeable about BBS, are good listeners and know how to talk to you about your life and future.

As you get older and become more confident, you may want to learn more about BBS and what you can do to stay healthy; it is important for you to be able to speak up for yourself so that your views and opinions can be heard. Learning about your healthcare needs and being able to talk to staff about how you feel is very important, and as you get older, you will be encouraged to ask your own questions at appointments and begin to see different healthcare team members on your own for part of your visit. This is called taking responsibility for your health and this can be hard to do if you are shy or you are not used to doing it. Tell the healthcare team that you are nervous or anxious about the appointment, they will give you lots of encouragement and support to help you to become more knowledgeable about BBS and involve you in decision making about your life.

Below are some questions and answers you may have about speaking up for yourself:

I don't have the confidence to speak to a doctor on my own. What should I do?

With the help of your parents/carers you can start building your confidence by preparing questions for members of the healthcare team before the appointment. You can write them down on a piece of paper or record them on your phone. The important thing here is that you ask the questions yourself – this is the start of you speaking up for yourself.

Do I have to go in to see the doctor on my own straight away?

You don't have to, but it is important to know that you can see the doctor on your own when you are ready. Remember that it is a gradual process and you shouldn't feel rushed. At first, the doctor will ask you some questions which may be about you, your school, what you want to do when you leave school and generally how you are feeling.

Will my parents/carers still be able to see the doctor if I go in on my own?

Yes, your parents/carers will have the opportunity to talk to your doctor with you which might be at the beginning or end of your appointment. It might be that they start off with you and then leave while you talk to the doctor on your own, or you may start the appointment with the doctor on your own and your parents/carers join you at the end. It's your appointment and once you have built up your confidence you can run your appointments the way you want to.



What if I want to ask the doctor something I want to keep private from my parents/carers?

Whatever you say to the doctor or any member of healthcare staff is strictly confidential and will not be passed on to your parents/carers without your permission unless you and/or other people are at risk of harm. If this is the case, the member of the team will discuss with you what parts of the information might need to be shared, who with, why it might be shared and how. This is to keep you as safe as possible.

Top tips when speaking to your healthcare team:

- ✓ Prepare a list of questions in advance
- ✓ Ask your doctors to use more simple language if you don't understand what they have said
- ✓ Learn more about Bardet-Biedl Syndrome so you can talk about how to manage it

My Questions: _____



Growing Up Wise



As you get older and become more independent, you may want to learn how to manage your money. You may start off with a small allowance or 'pocket money' to spend or save. Looking after your own money will help you to learn about budgeting, when to spend it, how to spend it, and how much to save. You may already be thinking about how to save for more expensive items instead of immediate treats.

Ask your parents/carers to help you work out how much you need to save and how long it will take to reach your goal amount. You can then think about how you would like to save your money which could be in a money box or in a savings account.

I enjoy spending my money on clothes shopping, but it's great to save some in my bank account and watch it grow.

Work experience and volunteering can be a fun way to meet new people and learn new SKILLS.



Health, Relationships and Lifestyle

Following a healthy lifestyle is really important and can help you cope with the changes that happen during your teenage years. Benefits of being active include:

- **Improved fitness** – regular exercise gives us more energy and strength and helps us stay a healthy weight
- **Improved mood** – exercise releases ‘happy hormones’ which make us feel good
- **Improved sleep** – being physically active during the day helps us sleep better at night

Following a healthy, well-balanced diet is really important too. When you have BBS it’s really important to be careful about the size of the portions you eat and fill your plate up with vegetables or salad. You should limit your intake of fizzy drinks, fruit juice and fast food. Your BBS healthcare team includes a dietitian who will treat you as an individual and work with you to identify possible diet and lifestyle changes and set achievable goals.





I'm really into sports and when I found out I had BBS, I didn't think playing sports would be possible. However, a whole new world opened up for me after I went along to a vision impaired cricket event. I won the best new player award at my first match.

Puberty

Adolescence is a time when your body starts to go through lots of changes and your emotions can sometimes feel out of control. Puberty is the name for the time when your body begins to develop, and physical changes take place as you change from a child to a young adult. During puberty, your body will grow faster than at any other time in your life, except for when you were a baby. You may start to feel irritable or moody and feel like no one understands you.

Everyone with BBS is an individual and puberty begins at different times for everyone. These changes and feelings are perfectly normal. Your parents/carers and healthcare team can help you to cope with the changes that will be happening to you. You may have lots of questions about the changes that are happening to you and about relationships and sex. Some adults are not comfortable talking about relationships and sex, but you can access information at school, from your GP, or family planning clinic.

Useful Websites

www.britishblindspport.org.uk

www.nhs.uk/live-well Articles, videos and tools from the NHS on more than 100 topics, including diet, fitness, tiredness and weight loss.

www.nhs.uk/change4life Website that gives top tips for a healthy diet and lifestyle.
Change4Life Food Scanner App: Scan barcodes using the app to find out how much sugar is inside popular food and drink.



Emotions



Everyone feels and displays emotions, ranging from happiness and excitement right through to anger and fear. We look after our emotional or mental health by having a full and happy life, having family members and friends who we can turn to for support, and being able to deal with the stresses that affect all our lives. Sometimes we can feel angry, anxious or even sad about things. This is perfectly normal for everyone, especially when you are a teenager when life can change very quickly.



Growing up with BBS can be difficult at times and you may have worries about what will happen in the future. It is important that you talk to your family, healthcare team and other professionals about your worries so that they can help you to find ways to cope and help you to live the life that you want.

If you are feeling very unhappy or you feel hopeless or worthless, it may mean that you need some extra help. Your GP, healthcare team or school staff can arrange for you to talk to a counsellor, therapist or psychologist who all have specialist training to be able to help you. Your BBS healthcare team includes a clinical psychologist who will talk with you in clinic about any difficulties you are having and consider what support you might need; you are not alone, help is available.

www.youngminds.org.uk is an excellent website with loads of information about mental/emotional health.

We feel more emotional, upset and fed up during puberty so we need to do things that make us happy.

Talking to people about how you feel can help you get through stuff.

Talking about my condition with my counsellor at school has really helped me with my thoughts and feelings.



Fun and Leisure

It is important to spend time with family and friends doing things you enjoy. You may like to go swimming, horseriding or to the cinema or park. Have a think about what you have got planned over the next week or so and think about new activities you would like to try – you may have written some ideas down in the first section, 'My Life, My Family'.

Talk to your parents/carers about how to access more activities that you enjoy and activities that will challenge you. Think about ways of making new friends; maybe you could join a club or activity group.



If you hang out with friends it might help you forget about any stress you have.





Keeping Safe

Growing up and becoming independent includes learning how to stay safe. If you are starting to go out independently, alone or with a friend, you should talk about how to stay safe with your parents. Discuss the rules below and add some more of your own:

- ✓ Take a mobile phone that has credit and a full charge
- ✓ Make sure your parents or a trusted adult knows where you are
- ✓ Stay within safe areas and areas that you know well
- ✓ If you ever feel unsafe or unsure, call your parents or a trusted adult



My friends have had mobility training which has helped if I need support from them. This helps me to have some independence without adults.

Our rules for staying safe: _____

Getting out and about

Some young people with BBS are partially sighted or severely sight impaired. They receive specialist support from a range of people, including Vision Impaired Specialist Teachers and Mobility Specialists. Mobility training provides support to young people who have low vision. They may learn how to get around using a cane, how to plan and follow a route in their local area or be taught strategies for staying safe when crossing roads. If you would like mobility training so that you can remain as independent as possible, speak to your parent/carers or healthcare team.

Social media and digital safety

Lots of young people spend quite a bit of time on the internet. Some young people have even said they prefer it to TV as it is more interesting, and they can do lots of things very quickly. Many young people know how to use a range of apps and can use game consoles for chatting to friends or accessing different areas of the internet. The internet and social media (Facebook, Twitter, Instagram, Snapchat, etc.) have brought a lot of exciting and interesting things to our lives, but unfortunately, they can also be scary and dangerous if not used safely.

Bullying

Bullying is behaviour that hurts someone else, such as name calling, hitting, pushing, spreading rumours or making threats. It can happen anywhere, at school, at home or online. It is usually repeated over a long period of time and can hurt, both physically and emotionally. From time to time young people may experience a thoughtless or unkind comment and there are different ways to deal with this including ignoring the comment, responding to it, or using humour. Bullying is different and needs to be dealt with. If you think you are being bullied, tell someone as soon as possible; this could be your parents, teacher, a friend or another trusted family member or adult.

Useful Websites

www.thinkuknow.co.uk

Information to help keep the internet safe and fun.

www.childline.org.uk

Information, support and advice, freephone:

0800 1111



Planning My Future

School, college, vocational studies or work are all part of life. As you get older you will start to have a bigger plan about what you would like to do and how you would like to do it, but don't worry if you aren't there yet – some young people know quite early on what they would like to do, for others it can take longer. You should be given opportunities at school or college to learn about possible future pathways; ask a trusted adult if you would like support with planning your future.

As you get older you will become more aware of how BBS affects you and the support that you need. Changing schools, starting college and other life changes will introduce new people into your life, and there may be times when you want to tell people about your condition or disability which can sometimes be difficult to do. Not telling anyone can sometimes make you feel that you're keeping a big secret. This may cause you stress or worry about being discovered. At times it can also make you feel that you are alone and no one understands.

Talking about BBS can be positive, as it may lead to:

- A sense of relief that it's no longer a secret
- Increased support from those around you
- Improved understanding from friends, teachers and others
- People understand more and can help out in difficult situations

Remember, you don't have to tell everyone everything. How much you disclose is up to you and may depend on your relationship with the person. There are those you may wish to tell very little, but for those people you trust, you may wish to tell them a little more. It may be useful to practice what you want to say so that it's not a big deal for you.

The Equality Act (2010) is a law that provides rights for people with an illness or disability. It may be really useful to tell schools, colleges or employers about your condition because they will then have to provide the support that you need – by law!



Learning to speak up and explain my difficulties to teachers wasn't easy at first but it really helped them to understand.

Transfer to Adult Services



Some young people feel very comfortable in children's services and they don't want to move to adult services, while other young people feel ready to move onto adult services and want this to happen as quickly as possible. Feeling nervous about moving somewhere new is quite natural; your healthcare team should have lots of discussions with you about the changes coming up. If your healthcare team have not started talking to you about your transfer to adult services and have not given you a timeline so that you can plan for when it will happen, don't be shy. Take control and with the help of your parents/carers, think about whether you want to ask them the following questions. You may want to add some of your own:

- When will I be moving to adult services?
- Can I choose which adult service I move to?
- What is the difference between the adult service and children's service?
- What do I need to know before I move to the adult service?
- Can I meet any of the adult service team before I leave the children's service?
- Can I visit the adult service to look around?
(This is sometimes called an orientation visit)
- Are there any young people I can talk to about moving to adult services?

Bardet-Biedl Syndrome Clinic

The team at the BBS Clinic will start talking to you about transition to adult services during your teenage years. You can transfer to adult services at any time from 16 years of age; when this will happen is for you to decide with your healthcare team and your parents/carers. At the new centre, you will find that some things are the same whereas others are a little bit different. You may see some familiar faces at the new centre as some of the team work in both children's and adults' services. Your BBS UK Support Officer will be able to tell you all about the adult service and answer any questions you may have; they will also be at the new centre and will continue to support you within adult services.

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 [@lmbbs1](https://twitter.com/lmbbs1)

 [YouTube](#)