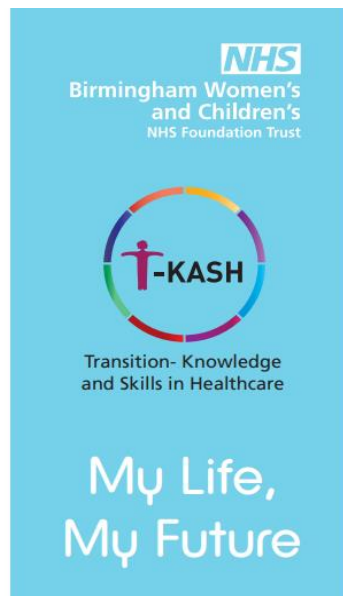




How-to guide, My Life, My Future, Transition Assessment Tool

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Person Centred Planning in a Healthcare Setting

My Life, My Future (MLMF) is a person-centred, transition planning tool, for young people from age 11+, who are living with long term health conditions. It can be used to consult with disabled young people or those who find it harder to speak up for themselves. It was originally based around *The Transition Pathway: guidance and tools to support person-centred transition planning with young disabled people aged 13–25. Transition Pathway Partnership, Scholl C, Dancyger F, Parsons M, et al. 2005.* In 2009 Marie McGee, Rare Diabetes, Transition Care Co-ordinator, Birmingham Women's, and Children's NHS Foundation Trust, adapted the tool to fit with transition in healthcare. MLMF has been updated and reviewed several times, and from 2016

this included the addition of Alstrom Syndrome UK (ASUK), Transition Knowledge and Skills (T-KASH) logos. The logos were originally created by young people from ASUK, Hear My Voice Youth Forum with some input from siblings, parents, and carers. These were updated in 2022, with the support of the Experts by Experience Advisory Group, from the Breaking Down Barriers Network and the ASUK youth and young adult advisors. With the inclusion of the updated T-KASH logos, MLMF is a more inclusive and accessible tool.



ASUK in conjunction with the Breaking Down Barriers Network have also created several educational resources that can be used to support positive transitions into adulthood. This includes an animation about transition in healthcare, a T-KASH poster and dedicated web pages aimed at young people, parents, carers, and professionals. More information about T-KASH can be found

www.breaking-down-barriers.org.uk/t-kash-transition-tools/

It's important to make transition in health work better for all young people and ensure that the tools and resources are accessible for young people with disabilities or those who find it hard to discuss their health or wider life. *MLMF* is a holistic and person-centred tool, which supports developmentally appropriate, structured conversations, identifying the YP self-care needs and their hopes for the future. *MLMF* can also be

used to assess the young people's knowledge and skills, covering a wider area of their lives including how to be a good self-advocate, keeping safe online or knowing where to go for support. There is a section in MLMF for parents/carers views, and opinions. MLMF is also accompanied by a Summary of Support document, which gives an overview of other professionals/agencies involved with the young person/family.

MLMF can be adapted for any clinic setting, it has been used extensively in Rare Diabetes, Rheumatology and with some Renal Patients. It really gives young people a chance to open up and discuss many aspects of their life. It has been used extensively with young people who have autism, selective communication styles, dual sensory loss, learning difficulties and/or developmental delay. Healthcare Staff find it a good starting point to be able to understand the young person's needs and work on a transition plan with them. Throughout the young person's transition journey, it is important to empower, educate and support the young person to develop the necessary knowledge and skills to manage their own healthcare.

Aims of MLMF

The aims of MLMF are to provide a person-centred planning tool that can:

- Break the ice...! It supports structured conversations around 12 aspects of a young person's life.
- MLMF enables, parents, carers, and professionals to identify the young person's knowledge and skills to manage their healthcare.
- Convey questions from the young person to the healthcare team that they may lack confidence to ask for themselves.
- Raise issues about areas of the young person's life that may be troubling them.
- It helps to identify information and signposting for the young person or other family members.
- Where permission is given to share information; MLMF can be used to inform young people's Education and Social Care Plans (EHCP) and Social Care / Care Act Deaf/Blind assessments.
- MLMF could also be used in other services and settings including the community and voluntary sector.
- MLMF and T-KASH can also be used in conjunction with Ready, Steady, Go, a suite of transition assessment resources <https://www.readysteadygo.net/home.html> with their origins based on the work of Dr. Janet McDonagh, Senior Lecturer, Paediatric and Adolescent Rheumatology, Birmingham Women's and Childrens NHS Foundation Trust.

MLMF; Recording Information

- MLMF provides many opportunities for discussion, recording, planning, and signposting.
- A young person can fill in the MLMF themselves or it can be written up by a key worker or supporter. At the bottom of each section there is a speech bubble that says 'Discuss.' These are prompts to broaden conversations about certain topics or help the young person to think more broadly about their life. If a key worker or supporter is guiding the young person through the MLMF plan they can ask the 'Discuss' questions.
- Sometimes young people may want to draw or write their own answers, with the key worker or supporter guiding the young person through the topic areas.
- The conversation does not have to follow the exact layout of MLMF. The format is a guide to extract the main points, so that an agreed transition plan can be put together by the key worker or supporter and the young person.

Top Tips

- Explain to the young person and family that MLMF is not a test, it's a way of finding out the young person's knowledge and skills in relation to their healthcare, lifestyle, and future.
- Healthcare staff should give opportunities for the young person to be seen independently (age, developmental needs and independence level need to be taken into consideration).
- Seeing the young person independently provides opportunities to build their confidence and gather their views rather than that of the parent or carer.
- Once a young person has filled in the MLMF plan or it has been scribed, it is fed back to the parent, carer by the young person or the key worker/support. Parent, carers thoughts, ideas, and responses are also added to the plan.
- In a clinical setting, young people can be encouraged to take the completed MLMF plan into their appointments with them to act as a prompt. Alternatively, it is given to the healthcare staff to discuss directly with the young person, parent, or carer.
- For young people who are seen regularly in outpatient appointments they can fill in the sections over time. If a young person is only seen once per year the whole document could be filled in. It takes between 30-40 minutes to fill in the whole plan, depending on the communication style of the young person.
- Some parent or carers may insist on filling in the MLMF Plan on behalf of the young person. This could be because they feel the young person's level of

communication may need interpreting by them. To follow this up, always give the young person (independently if possible) time to go through what the parent, carer has filled in on their behalf. The young person's views can always be gathered separately from the parent or carer during the clinic appointment/s.

- Ensure that the clinic summary letter has a section that records the transition plan along with the young person's views, opinions, and any signposting from the MLMF. Also highlight the knowledge and skills the young person is developing.
- Once a young person has been prepared for transfer, an orientation visit has been carried out (where possible) and a date for transfer has been agreed with the young person, an up to date MLMF can be recorded with the young person and sent to the adult team. This will give a good insight into the young person's ideas, concerns, skills, and knowledge. Sharing this information acts as an excellent ice breaker for the adult team.

MLMF-YP Core Knowledge and Skills (KAS)



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Each section of MLMF is linked to several knowledge and skill areas that young people can develop as they mature and move into adulthood. They can be used to generate discussions, to support young people to identify where they need support, training, or information.



Me, My Life, My Family

This is all the things I like doing, my dreams, my wishes and getting on with people at home.

Knowledge and Skills

- Young people getting to know themselves.
- Being able to talk about themselves confidently.
- Thinking about their future.
- Develop independence and responsibility.
- Managing trips, locally, overnight, or away from home.
- Managing their home life.
- Getting on with family members.





My Culture, My Beliefs

How I live my life through things like; my language and religion, the food I eat, clothes I wear and music I like.

Knowledge and Skills

- Being able to talk about their own religion, culture, and beliefs.
- Knowing about other religions, cultures, and beliefs.
- Being part of a multi-cultural society.
- Respecting others and being respected for their own identity.
- Knowing who to talk to if the young person cannot access health services fairly





Growing Up Wise

Opening a bank account, managing money on a budget, planning my time and know where to go for information.

Knowledge and skills

- Identifying and recognising the value of coins and notes.
- Using technology and the internet for money management.
- Learning how to budget.
- Young people knowing about their benefits.
- Supporting young people to plan and manage their time.
- Knowing what organisations there are to help and provide further support.



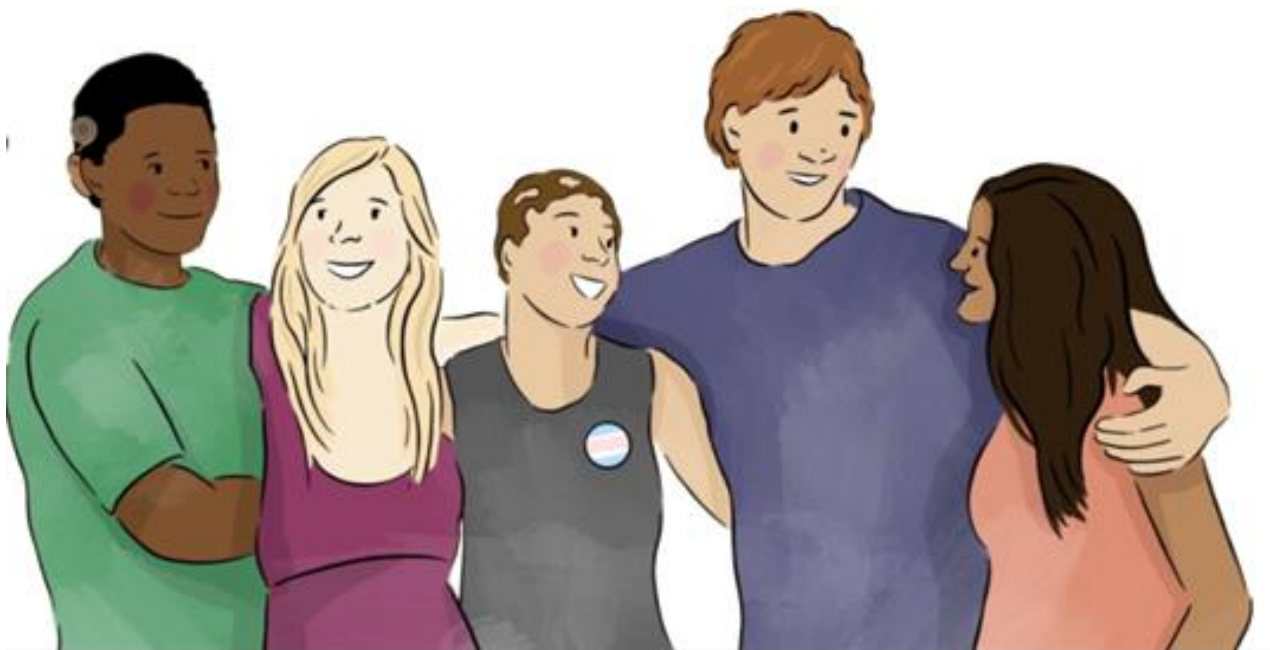


Keeping Safe

Telling someone if I'm being bullied, being safe online, and looking after myself when I'm out with friends.

Knowledge and skills

- Supporting young people to be safe on online.
- Supporting young people to be safe on social media.
- Informing young people of who they can talk to and where to go if they have any safety worries.
- Teaching coping strategies.
- Helping them to identify who their friends are.
- Supporting them to know the difference between an online friend or a friend they have met in person.





Fun and Leisure

Going out with my friends, doing things I like, having a laugh!

Knowledge and skills

- Supporting young people to know how to contact their friends.
- Teaching how to be safe when going out with friends.
- Informing about disclosure.
- Giving ideas and signposting to encourage an independent social life.
- Giving ideas and signposting to be part of clubs/societies.
- Giving ideas and signposting for hobbies/leisure pursuits.





My Emotions

Looking after your emotions, knowing who to talk to and where I can go for help.

Knowledge and skills

- Building self-esteem and emotional wellbeing.
- Building confidence.
- Encourage a positive body image.
- Support young people to feel safe and talk about issues such as bullying.
- Supporting young people to identify and manage emotions.
- Support to develop coping strategies.
- Ideas and signposting to further support networks.





Speaking Up for Myself, Making Decisions

Asking my own questions, seeing healthcare staff on my own, understanding my rights and responsibilities, making my own decisions.

Knowledge and skills

- Encourage young people to ask their own questions.
- Prepare young people for independent consultations.
- Manage young people to have independent consultations.
- Supporting young people to understand confidentiality, capacity, duty of care and disclosure.
- Improve communication and decision-making skills.
- Supporting young people to take control of their own self-care.
- Advise young people about their health, rights and responsibilities.
- Support and encourage young people to develop self-advocacy skills (speaking up for themselves).





Health, Relationships and Lifestyle

Healthy eating, exercise, shopping, cooking, getting around safely, relationship education including what's safe to do in a relationship.

Knowledge and skills

- Supporting young people to understand how daily exercise can improve wellbeing.
- Educating young people to understand the importance of healthy eating.
- Understanding that a healthy lifestyle contributes to emotional and social wellbeing.
- Advising about regular dental checkups.
- Educating young people about the effects of smoking, alcohol, and substance misuse.
- Educating young people about puberty and growth.
- Supporting young people to manage their periods.
- Advising about sleep and knowing how to deal with tiredness or fatigue.
- Understanding sexual health (inc safe sex practices).
- Inform young people about access to sexual health services.
- Support with pregnancy.
- Education young people about good self-care.
- Encourage young people to take part in household chores.
- Support young people to be able to shop for food, know how to make a snack/drink or make a meal.
- Advise and signpost for mobility issues, aids, equipment, and how to get around safely.





Knowing about My Medical Condition/s

Being able to talk about my medical condition, describe how it affects my body, knowing about what medication I take and what it does.

Knowledge and skills

- Support young people to be able to describe their condition and/or symptoms.
- Support young people who have an undiagnosed condition, explain any additional investigations/tests and signpost to additional support networks such as the charity SWAN (Syndromes Without A Name) www.undiagnosed.org.uk
- Understand their medication and its effect on their body.
- Understand when and how to take their medication and any aids additional support available.
- Supporting young people to know how to manage pain.
- Inform young people about the roles of professionals in their life.
- Educate young people to understand medical terms.
- Understand prognosis (the possible course of a medical condition).
- Signpost to patient organisations and other support networks.



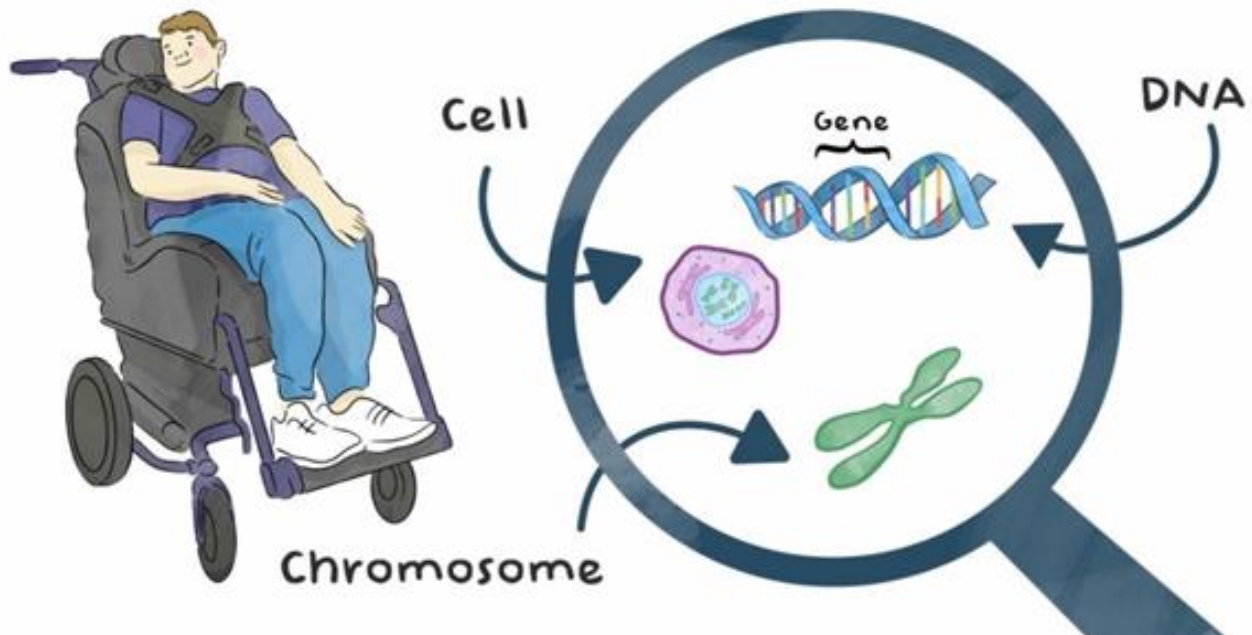


Genetics and Me

It's important to understand my genetics and know how my genes are passed on.

Knowledge and skills

- Support young people to understand if their condition is genetic.
- Explain inheritance patterns.
- Educate young people to understand genetics, and how genes, behaviour and the environment can impact our health.
- Advise young people about planning for a family or parenting.
- Signpost for further information about genetics and tests available.





Transfer into Adult Services

Planning and preparing for big changes in my routine, including transferring into adult services and taking more responsibility for myself (includes moving from children's to adult hospital's)

Knowledge and skills

- Supporting young people to know the meaning of transition and transfer.
- Supporting young people to know the difference between adolescent and adult services.
- Advise and support young people to move onto independent visits with healthcare professionals, if appropriate.
- Prepare young people for transfer into adult services.
- Educate young people to learn how to contact adult services.





Planning My Future

Becoming more independent, getting a good education, volunteering, finding work, developing life skills, having the best life possible

Knowledge and skills

- Support young people with their future plans- this can include school, college, developing life skills, etc.
- Educating, advising and supporting young people to help improve their sense of control (Living their life the best way possible for them).
- Supporting young people to understand the impact of their condition/s on career choices.
- Educate and advise about how and when to disclose positively.
- Support and advise about work experience (where possible)
- Support young people to develop daily living skills.
- Support young people to develop a career plan.
- Advice young people about reasonable adjustments and access to work.
- Support young people to get the best from life regardless of their condition or disability.



For further information and recommendations for developing transition services.

- Inbetweeners report reviewed the barriers and facilitators in the process of transition of children and young people with complex chronic health conditions into adult services. National Confidential Enquiry into Patient Outcome and Death (NCEPOD) 2023
- NICE: Transition from children's to adults' services for young people using health or social care services (NG43)
- NICE: Transition from children's to adults' services (QS140)
- CQC: From the pond into the sea
- RCPC: Facing the Future: Standards for children with ongoing health needs
- DHSC: Quality criteria for young people friendly health services.
- Together for Short Lives: Stepping Up. Transition to Adult Services Pathway
- Welsh Government: Transition and handover from children's to adult health services
- Intensive Care Society: Paediatric to adult critical care transition
- WellChild: 8 Principles for Transition



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