Transition to Adulthood

A practical guide for families affected by Kabuki syndrome in Scotland

For families of a young person with Kabuki syndrome, moving from childhood to adulthood can feel complicated. Parents and carers may have organised appointments, worked with schools, managed benefits and finances and helped with decisions for many years. As their child grows older, different legal rules and services begin to apply.

There is no single day when everything changes. In Scotland, some important decision-making changes occur at **16**, while benefits, education and other services may change at different times. Planning early can help prevent gaps in support.

Where do I start?

From around age 14, families may want to begin thinking about:

- education, training, employment and volunteering
- health and transfer from paediatric to adult services
- friendships, relationships, hobbies and the community
- independent or supported living, housing and care
- benefits, banking, savings and Child Trust Funds
- decision-making, powers of attorney and possible guardianship
- wills, inheritance and trusts
- the young person's wishes and aspirations for adult life

Not everything will apply to everyone. Some people with Kabuki syndrome will make their own decisions and live independently. Others may benefit from support with particular decisions or require substantial ongoing assistance. The starting point should always be the young person's abilities, preferences and ambitions.

Decision-making and capacity

The **Adults with Incapacity (Scotland) Act 2000** provides a framework for decisions involving adults aged 16 and over who cannot make or act on particular decisions because of incapacity. It is different from the Mental Capacity Act used in England and Wales.

Capacity is not an all-or-nothing label. A young person might choose their food, activities and friends, but need help with an unfamiliar financial or legal decision. A diagnosis of Kabuki syndrome or learning disability does not by itself establish incapacity.

The Scottish framework requires that interventions benefit the person and are the least restrictive option likely to achieve that benefit. The person's wishes and feelings must be considered, along with the views of relevant others. Families and professionals should explore practical communication and decision-making support.

Being a parent does not, by itself, provide unrestricted legal authority to control a young adult's money or welfare decisions. Ask what authority, if any, is actually necessary for each task.

Scottish powers of attorney

A person with capacity to understand and grant the document can appoint a trusted person under a **Scottish continuing power of attorney** (for property and finances), a **welfare power of attorney** (for personal welfare) or a combined document. These are not the England-and-Wales LPA forms.

A continuing power can be drafted to operate when the person chooses, subject to registration and its terms. Welfare powers can be used only when the person lacks capacity for the relevant welfare decision. The document must be certified by an appropriate solicitor or medical practitioner and registered with the Office of the Public Guardian (Scotland).

A parent cannot simply create a power of attorney on behalf of an adult who cannot understand the grant. A solicitor familiar with adults with incapacity can advise on capacity, suitable powers, safeguards and substitute attorneys.

Office of the Public Guardian (Scotland) – powers of attorney

What if my son or daughter cannot make a power of attorney?

Where the person lacks capacity and formal authority is needed, there are Scottish alternatives. The appropriate option depends on the particular decision, the complexity of affairs and whether authority will be needed once or repeatedly.

- Guardianship order: an application to the sheriff court for ongoing financial and/or welfare powers. The order sets out exactly what the guardian may do.
- Intervention order: a court order for a particular action or decision, for example a specific property transaction.
- Access to Funds scheme: for relatively straightforward financial needs, an authorised person may be allowed to access funds for day-to-day expenses through the Office of the Public Guardian.

These are not the same as Court of Protection deputyship and there is no Scottish COP3 application process. Court applications generally require reports from relevant professionals and may involve court, legal and reporting costs. Legal aid may be available in some circumstances; ask a Scottish solicitor or the Scottish Legal Aid Board.

Useful tip: a Scottish guardianship application can be made up to three months before a young person's 16th birthday, with the order taking effect at 16. If significant ongoing decisions may be needed, obtain advice well before that birthday.

Office of the Public Guardian – guardianship orders

Office of the Public Guardian – Access to Funds

Bank accounts, savings and Child Trust Funds

Money in a young person's name belongs to that young person. Parents do not automatically gain access to it simply because they originally contributed it or act as carers. Different banks and providers may require evidence of legal authority before allowing someone else to operate an account.

A Child Trust Fund usually matures at 18. If the young person can manage the money, they can deal with the provider themselves, with appropriate support. If they cannot, ask the provider and a Scottish solicitor what authority is required. Depending on the situation, Access to Funds, an intervention order or financial guardianship may be appropriate.

Check account ownership, documentation and any upcoming maturity dates early, especially if sizeable savings or investments are involved.

Benefits and becoming an appointee

An appointee can act on someone's behalf in relation to specified benefits where they cannot manage their claim or payments. This is different from acting as attorney or guardian and does not automatically confer control over all bank accounts, savings or property.

Social Security Scotland has arrangements for appointees for Scottish benefits. The Department for Work and Pensions has separate arrangements for UK-wide benefits such as Universal Credit. Ask the relevant organisation what authority is needed rather than assuming an existing appointment covers everything.

Child Disability Payment and Adult Disability Payment

In Scotland, **Child Disability Payment (CDP)** normally continues until 18. From 16, a young person can choose to apply for **Adult Disability Payment (ADP)**; moving between them is **not automatic**. A young person may remain on CDP between 16 and 18 while considering when to apply, but a new ADP application is generally needed before their 18th birthday to avoid interruption.

Social Security Scotland may contact families around age 16 about who will manage the young person's payments. Applying for ADP may affect the amount received or other linked benefits. Seek an individual benefits check before changing claims.

Some young people may qualify for Universal Credit at 16 or 17 in particular circumstances, but rules are restrictive, especially for full-time education. Families should take specialist advice before applying, including about interactions with their own benefits.

Social Security Scotland – moving from Child to Adult Disability Payment

GOV.UK – become an appointee for someone claiming benefits

Wills and planning for the future

Parents and carers may wish to review their own wills, executors and plans for who could support their son or daughter when they are no longer able to. Leaving a large sum directly to a disabled beneficiary can be problematic if they cannot manage it, and an inheritance can affect means-tested assistance.

Questions for a Scottish solicitor include whether a trust is appropriate, who should serve as trustees, how money could be used for the young person's benefit and how Scottish succession law and tax rules apply. Scottish succession rights and will-making rules differ from those in England and Wales.

Disabled person's trusts and vulnerable beneficiary trusts

A trust allows trustees to hold or manage money and property for someone else's benefit. In some circumstances a carefully drafted trust can support long-term planning and may have special tax treatment for a qualifying disabled or vulnerable beneficiary. The detailed conditions matter and should not be assumed to apply to every trust.

Seek advice from a Scottish solicitor with experience of disability planning, trusts and tax before setting one up. It is important to consider trustees' responsibilities and how the arrangement might interact with social care and benefits.

GOV.UK – trusts for vulnerable people

Can a young person make their own will?

Some young adults with Kabuki syndrome will be able to make their own will. The relevant issue is whether the person has the necessary capacity for making a will, which is not identical to being able to manage every aspect of daily finances.

In Scotland, do not assume that an attorney or guardian can simply make a will for another person, or that the England-and-Wales statutory-will route applies. Specialist Scottish legal advice is particularly important if there are significant assets or questions about testamentary capacity.

Health and moving to adult services

Paediatric and adult health services can operate very differently. Families who have always spoken directly to clinical teams may encounter different approaches to consent, confidentiality and involvement as the young person gets older. Discuss communication needs and supported decision-making well before transfer.

Useful questions to ask each clinical team:

- When will transition start, and which adult team will take over?
- Will there be a joint appointment or written handover?
- Who will coordinate care if several specialties are involved?
- What happens if no equivalent adult specialist service exists?
- What adjustments are needed for communication, appointments and examinations?
- How will the young person's consent and family involvement be handled?

Annual learning-disability health checks

In Scotland, NHS annual health checks are available to people aged **16 or over** with a learning disability or who think they have one. The GP practice or local health board can advise about arranging a check. The visit can help review ongoing health needs, medicine, specialist referrals and reasonable adjustments.

NHS inform – annual health checks for people with a learning disability

Health and care passports

A health or hospital passport can set out important information, including medical history, medication, communication methods, how someone expresses discomfort, sensory preferences, routines, key contacts and reasonable adjustments. Ask the local NHS board which format is most useful. Keep it updated and involve the young person as fully as possible.

Education and moving on from school

Scotland has an **Additional Support for Learning (ASL)** framework rather than Education, Health and Care Plans (EHCPs). Some young people have a **Co-ordinated Support Plan (CSP)**, while others have different support arrangements. There is not a Scottish equivalent of an EHCP entitlement continuing automatically to age 25.

Post-school planning should consider further education, training, apprenticeships, employment, volunteering, independent living and community life. Involve Skills Development Scotland, colleges, NHS services, social work and other providers when relevant.

For school leavers whose needs are covered by the statutory transition duties, the education authority must seek and take account of information from appropriate agencies **no later than 12 months before leaving school** and pass relevant information to agencies **no later than six months beforehand**. Good planning starts even earlier.

Ask who is coordinating the transition, when college or training support will be confirmed, what specialist assistance is available and what happens if the planned destination is unsuitable or unavailable.

Scottish Government – guidance on transitions

Enquire – advice on additional support for learning

Adult social care and Self-directed Support

Where ongoing care and support are likely to be needed, ask the local authority or Health and Social Care Partnership about assessment and planning before the transfer from children's services. Consider personal care, equipment, respite, community access, travel, housing, supported living and employment support.

Scotland uses **Self-directed Support (SDS)**, which provides four broad ways of arranging assessed social-care support, including a direct payment, support arranged by the person, council-arranged services or a combination. Families should ask for clear information on assessed need, eligibility, available options and any charging rules.

Carers can also request an **Adult Carer Support Plan**, looking at their own needs, wellbeing, ability to continue caring, emergency arrangements and available support. Planning should reflect the young person's aspirations, not just basic safety.

mygov.scot – Self-directed Support

mygov.scot – Adult Carer Support Plan

A simple transition checklist

From around 14

- ☐ Discuss what the young person wants from adult life.
- ☐ Ask school for a coordinated post-school transition plan and named lead.
- ☐ Talk with health teams about adult-service handovers and a health passport.
- ☐ Begin exploring future education, work, friendships and independent living.

Around 15–16

- ☐ Understand the Adults with Incapacity framework and supported decision-making.
- ☐ Ask whether Scottish power of attorney may be appropriate or whether guardianship advice is needed.
- ☐ If necessary, investigate guardianship well before 16.
- ☐ Check who will manage Scottish benefits and whether an appointee is needed.
- ☐ Review Child Disability Payment and Adult Disability Payment options.

Around 16–18

- ☐ Check Universal Credit eligibility and effects on household benefits.
- ☐ Review bank accounts, Child Trust Funds and savings; check maturity dates.
- ☐ Confirm school-leaving transition duties and arrangements with post-school providers.
- ☐ Ask adult social care for assessment and discuss Self-directed Support.
- ☐ Check whether annual learning-disability health checks are being offered.
- ☐ If moving from CDP to ADP, submit the necessary application in good time.

For parents and carers

- ☐ Review wills, trusts and future financial provision with a Scottish solicitor.
- ☐ Consider who could offer support if parents were no longer able to.
- ☐ Discuss housing, care and emergency support plans.
- ☐ Keep health history, contacts, routines and communication preferences accessible.
- ☐ Involve the young person in every stage wherever possible.

Recommended reading and useful resources

These resources are a useful place to begin, but eligibility and individual circumstances can be complex. For legal or benefits decisions, seek Scotland-specific advice.

Office of the Public Guardian (Scotland) — Information on powers of attorney, guardianship, intervention orders and Access to Funds.

Office of the Public Guardian (Scotland)

Scottish Government – transitions guidance — The duties and practical steps associated with moving beyond school.

Scottish Government transitions guidance

Enquire — Free advice on additional support for learning and education transitions in Scotland.

Enquire · additional support for learning

Social Security Scotland — Child and Adult Disability Payments, appointees and local support.

Social Security Scotland

NHS inform — Information on annual learning-disability health checks and access to healthcare.

NHS inform · learning disability health checks

Self-directed Support Scotland — Independent information about options for managing social-care support.

Self-directed Support Scotland

Contact — Advice and information for families with disabled children, including transitions.

Contact · preparing for adult life

One final thought

Transition should not simply mean replacing the tasks parents currently do. It is a chance to ask a bigger question: **what does a good adult life look like for this young person?** The answer might include college, work, volunteering, friendships, relationships, sport, travel, supported living or greater choice and independence. It will be different for every person with Kabuki syndrome.

Important: This guide provides general information for families in Scotland and is not individual legal, benefits, medical or financial advice. Rules and services can change, and families should seek appropriate professional advice about their own circumstances. Updated October 2026.