

CHAPTER 13

Transition to adult care

Jenny Prüfe

Department of Paediatrics II, University Hospital of Essen, Essen, Germany.

ORCID:
<https://orcid.org/0000-0001-7565-295X>

Nowadays, most children with chronic kidney disease (CKD) stage 5 and kidney transplantation survive into adulthood. As a result, healthcare transition from paediatric into adult (nephrological) care becomes necessary. Transition is a deliberate process designed to support the development of young patients and help them become self-reliant adults who understand and actively manage their condition. During this process patients gradually take responsibility for their own health care in line with acquired skills and competencies, while their main caregivers step back and become supervisors rather than actors. “Transfer”, on the other hand, refers a specific point in time when care is handed over from one health care provider (paediatrician) to another (nephrologist).

The 5 Ws of transition can be summarised as follows:

- **Who:** paediatric (renal) patients and their carers
- **What:** a focused process to help patients and their families acquire the knowledge and skills needed to manage the chronic condition, including the medical, psychosocial, educational and vocational aspects of living with progressive chronic kidney disease
- **When:** as soon as possible, but no later than 12 years of age, until the patient is transferred out (usually around 18 years of age)
- **Where:** in out-patient clinics and, in later stages, in collaboration with the continuing adult nephrologist
- **Why:** to improve long-term outcomes by helping patients to take responsibility for their own health needs.

With regard to age, it is important to recognise that the age of transition is often determined by the prevailing legal and regulatory framework. This is a highly unfavourable situation, as readiness for transition cannot be determined by a

calendar age. Rather, it depends on a number of factors, including the child's development, social network, health stability and the success of several years of preparation. To illustrate, a child may not begin the transition process at the age of 12 years because the centre does not have the resources to facilitate early transition, or because the child and parents are not ready. Similarly, a patient may be transferred out at the age of 18 years, despite the presence of suboptimal conditions, because of compelling regulatory reasons. This highlights the importance of more flexible processes and regulations to allow for paediatric patients to be transferred when they are ready, regardless of age.

The aims of transition are (i) educating the patient about the disease and treatment, (ii) facilitating the patient's decision making, and (iii) supporting future caregivers to ensure optimal health care. According to the German S3 guideline on transition [1], the following aspects should be considered:

1. An individualised transition plan should be drawn up, with planned actions individually defined and timed;
2. Readiness for transition should be assessed in a detailed clinical interview;
3. The timing of transition should not be strictly linked to the patient reaching legal adulthood (18th birthday), but should take into account patient and condition specific needs (e.g. complex condition requiring more than one health care transition);
4. The transition process should include education of the patient and, where appropriate, their parents/carers on relevant aspects of the disease and the transfer itself;
5. An interdisciplinary approach to transition should be taken, including allied health professions and non-medical specialists specific to the patient and health condition;
6. At the time of transfer, a structured medical letter should be provided to the patient and future caregivers, including details of the history and course of the illness, psychosocial needs, and any findings relevant to previous and/or future treatment;
7. A designated transition key worker should accompany and oversee the transition process and act as a point of contact for all others involved;
8. To improve adherence, low-threshold services should be used as reminders and sources of information through appropriate internet services, apps, SMS, email and/or telephone where available;
9. In younger adolescents, parents/caregivers should generally be involved in the transition process. Where appropriate and agreed with the patient,

- parents/carers should be involved beyond the transition. For patients with cognitive impairment, parent/carer involvement is mandatory;
10. The offer of a joint consultation or case discussion involving both the paediatrician and the continuing adult physician should be considered;
 11. To support the transition process, several of the elements described in the guidelines should be effectively combined rather than applied in isolation;
 12. Conversations about transition should begin as early as possible and be developmentally appropriate;
 13. Issues relevant to adolescents, such as sexuality, family planning, sleep-wake patterns, use of alcohol, nicotine and illegal substances, and their interaction with the disease and its treatment, should be addressed during the transition process;
 14. Screening for mental health and psychological distress should be an integral part of the treatment routine;
 15. Sufficient time should be allocated for detailed transition discussions in paediatrics, but also with the future health care provider;
 16. Responsibility for disease management should be gradually transferred from parents to the young person;
 17. Counselling should be offered to young people on professional and social issues related to the chronic condition;
 18. Young patients should be referred to self-help groups and patient organisations that are relevant to them. Self-help groups and patient organisations can be involved in shaping the transition process.

Transition is a complex process that involves patients, parents, healthcare providers and various members of the multidisciplinary care team all working towards the same goal. However, there can be various barriers to successful transition. Such barriers may arise at different levels. Being aware of these barriers can help to alleviate them. A selection of possible barriers is shown in Table 1.

Table 1 Barriers to successful transition to adult care

Individual barriers (patient level)	Social barriers (parents, peers, school and work)	Structural barriers (health care system)	Professional level (health care professionals)
Striving for normality	Overprotective parenting	Lack of resources (finance, staff, transition clinics)	Specific paediatric conditions not part of adult nephrologist training (syndromes and congenital conditions)
Increased risk-taking behaviour as part of adolescent's development	Negligent parenting	Lack of transition staff and structures	Complex conditions requiring more than one speciality in adult care
Limited executive function/impulse control/action planning	Parents not transferring responsibility	Lack of professional intervention	Challenges in learning about rare conditions
Cognitive impairment	Peers challenging behaviour	Lack of psychosocial support in adult care	Workload: more patients – less time per patient
Lack of autonomy and self-care skills	Lack of social support and acceptance	School/working hours interfere with medical needs and physician office hours	Little education about adolescent medicine and treatment of a still developing body
Lack of disease and treatment specific knowledge		Rigid timing of transition (age not readiness)	

Optimal transitional care is provided in a clearly structured way. However, there are no comprehensive transitional programmes in Germany. Although the KfH (Kuratorium für Dialyse und Nierentransplantation e.V.) offers patients the opportunity to participate in “Endlich Erwachsen” (Finally Adult), this programme is a valuable addition, but it is disconnected from the patient’s routine care. In the UK, ‘Ready – Steady – Go’ is an established generic tool to facilitate transition, regardless of the underlying medical condition. It provides a structured training programme alongside regular clinic visits and promotes an individualised approach to empowering patients [<https://www.readysteadygo.net/rsg.html>].

To avoid overwhelming the patient, the time of transfer should be planned carefully and too many changes should be avoided at once. Ideally, the transition itself should be gradual, with joint or alternating appointments and a gradual transfer of responsibility from the paediatrician to the nephrologist. In this way, both doctors and patients can get to know each other and refer back to each other until they feel comfortable handing over care. The timing should not be based on age but on ability: a patient may be ready for transfer at any time when:

- Allograft function is stable
- Health literacy and medication adherence are well established
- Patient is emotionally stable (no acute adverse life events)
- Social functioning is established (school completed, supportive environment)
- Health services are established (nephrologist appointed for ongoing care, health insurance coverage is secured).

Successful transition is a time-consuming and costly process. But it will result in a competent patient, a confident adult nephrologist and a favourable medical outcome with stable allograft function. To achieve this, the combined efforts of patients and professionals are essential.

References

- 1 Gesellschaft für Transitionsmedizin. S3-Leitlinie: Transition von der Pädiatrie in die Erwachsenenmedizin. Version 1.1 vom 22.04.2021. Verfügbar: <https://www.awmf.org/leitlinien/detail/ll/186-001.html> (01.06.2024)