

# CHAPTER 12

## Social-legal aspects in paediatric kidney transplantation

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From the moment of diagnosis, chronic terminal kidney disease becomes a life-long companion for the child and their family. Although the therapy changes with the transplant, the child remains chronically ill and requires ongoing medical support. In Germany, chronically ill people are entitled to a range of material, financial and non-material forms of compensation for the disadvantages they face. In the case of minors, applications must be submitted by their legal representatives. Advice on social entitlements and assistance in claiming them is provided by the social services staff at the treatment centres. Families often benefit, if the attending physician also has information about possible sources of assistance and can make specific referrals. An overview of this is provided in this chapter.

The entitlements of those affected are derived from the books of social legislation, which also regulate the procedures for applying for and granting these entitlements. The most important of these are:

SGB V → Statutory health insurance benefits and their relationship to service providers (“gesetzliche Krankenversicherung”)

SGB VI → Statutory pension insurance benefits, e.g. relevant for rehabilitation benefits (“gesetzliche Rentenversicherung”)

SGB VIII → Child and Youth Welfare, e.g. relevant for services for integration assistance for children with (impending) mental disabilities and child day care services (“Kinder- und Jugendhilfegesetz”)

SGB IX → Rehabilitation & Participation (Rehabilitation and Severely Disabled Persons Act and Integration Assistance/“Bundesteilhabegesetz”)

SGB XI → long-term care insurance, e.g. relevant for claims and benefits in the event of a need for long-term care (e.g. aids) (“gesetzliche Pflegeversicherung”)

In detail, this results in the following benefits to which patients may be entitled after a kidney transplant. We have not included specific reimbursement rates, as these are regularly adjusted. In addition, we have not listed all services that are theoretically possible, but only those that play a role in everyday clinical practice and require a doctor's prescription or certificate.

### **Benefits from statutory health insurance**

*Patient transport* is regulated in conjunction with the patient transport guidelines. This implies that there must be a medical necessity to justify the prescription and that the mode of transport is selected accordingly. While this can generally be assumed in the case of dialysis treatment, the medical necessity after transplantation is determined by the patient's immune status and any other pre-existing impairments. In the event of an uncomplicated course of treatment, travel costs associated with "post-inpatient treatment" are covered for a period of three months following the transplantation. Other relevant health conditions, e.g. for patients with complex illnesses, must be examined separately.

In principle, trips for outpatient treatment require prior authorisation, i.e. a doctor's prescription must be submitted to and approved by the payer before the trip begins. Exceptions are made for patients who are certified on their Disability Pass as having exceptional walking disabilities, blindness or helplessness on their severely disabled person's pass, as well as for patients with care level 4 or 5, and care level 3 in combination with a permanent mobility impairment. Trips made in the family's own car are only partially reimbursed according to the German SGB V. However, trips to the hospital and outpatient clinic should be documented and confirmed by the centre so that they can be taken into account for tax purposes.

In the case of hospitalisation, it should be noted that visits are generally not reimbursable. The situation is different if the presence of the parents – regardless of the child's age – is medically or psychologically necessary. This applies for example, to educational discussions or medical crises and should be certified by a doctor.

If medically necessary, a *parent or legal guardian* may also be *admitted* during an inpatient stay [1]. Co-admission is considered medically necessary if separation from the parent/primary carer would otherwise jeopardise the success of treatment. The health insurance companies decide up to what age the need for co-admission of a parent is considered to be age-related (usually around the

age of 9 years). If the parent cannot be accommodated in the patient's room due to lack of space, the costs of a nearby guesthouse or hotel may be covered if the medical necessity is certified and proof of the costs incurred is submitted to the health insurance company.

If a child's illness prevents their parent from working, they can claim wage replacement benefit (also known as child sickness benefit) for a limited number of days per child per year. To qualify for wage replacement benefit, a doctor's certificate confirming the child's illness must be submitted. In cases where the child's prognosis is limited to a few weeks or months – as outlined in § 45 Para. 4 SGB V – the entitlement to wage-replacement benefit is unlimited.

If there is another child under the age of 12 years living in the household or a disabled child who is dependent on assistance, the provision of *household assistance* may be granted for a maximum of 8 hours per day to help the family with its domestic tasks, provided that one of the parents also takes care of the child.

*Preventive care and rehabilitation measures* are also covered. A distinction is made between father/mother/child rehabilitation, child rehabilitation and family-orientated rehabilitation (FOR). After transplantation, family-oriented rehabilitation (FOR) is given the highest priority, as it is not only aimed at the sick child but also offers support to the parents and healthy siblings. In contrast, paediatric rehabilitation focuses on the chronically ill child. Parents may be allowed to accompany their child on the programme, but siblings are not included. It is important to note that all the benefits described here apply within the framework of statutory health insurance. Different rules may apply to privately insured persons and recipients of benefits.

### **Benefits from the statutory pension insurance scheme**

The pension insurance fund is responsible for measures for rehabilitation and participation in working life. Like the health insurance fund, it is responsible for covering the costs of rehabilitation measures. While the health insurance fund and the pension insurance fund may share the costs of rehabilitation before the patient enters working life, the pension insurance fund becomes the main provider of benefits as soon as the patient is in vocational training, military or civilian service and the aim of the rehabilitation is to maintain or restore the patient's ability to work.

In contrast to the health insurance system, the pension insurance system's right to request and choose a measure is primarily limited to contracted centres. If the pension insurance fund does not name a suitable contract centre from the patient's point of view, a medical report is required for the selection of a place of rehabilitation outside the contract centres. The statutory pension insurance funds also provide benefits for participation in working life according to §§ 49–54 SGB IX as well as in the introductory procedure and vocational training area of the workshops for disabled people according to § 57 SGB IX (see below).

### **Child and youth welfare services**

Child and youth welfare services are by no means limited to educational assistance and the protection of children's welfare. Child and Youth Welfare also acts as a rehabilitation organisation for children and young people who are threatened or affected by so-called "mental disabilities". In accordance with the provisions of SGB IX, the Youth Welfare Office is empowered to provide integration assistance in the event of an (imminent) mental disability, e.g. for educational and therapeutic services outside the remit of other organisations. This is the case, for example, when children and young people develop mental or behavioural problems as a result of specific learning difficulties. In the case of manifest concentration disorders, dyscalculia or dyslexia, learning therapy can be applied for as an educational-therapeutic measure, the costs of which are covered by the Youth Welfare Office.

The Youth Welfare Office also provides services to support children in day care centres and with childminders. This includes creating the conditions for a child with a kidney transplant to attend a day care centre, such as a crèche, day care centre or kindergarten. In addition, if necessary, the Youth Welfare Office provides support with inclusion, for example by providing integration assistants.

### **Rehabilitation and participation services**

The primary objective of the Ninth Chapter of the Social Code (SGB IX) is to regulate entitlements and measures for people with severe disabilities in order to enable them to participate in society. According to Section 2 of SGB IX, a person is considered to be severely disabled if he or she has a degree of disability of at least 50% and his or her place of residence, habitual abode or employment falls

within the scope of this Code. This status applies to all persons who have undergone a kidney transplant, as the degree of disability is at least 50% after a recovery period of two years post-transplant.

Official recognition of this status and the issue of a severely disabled person's card is based on an application to be submitted by the person's legal guardian. The resulting benefits depend on the degree of disability determined and any additional characteristics recognised. These include tax allowances of varying amounts, reduced/free use of public transport, assistance under the Housing Assistance Act and housing benefit, reduction or exemption from telephone and radio licence fees, and special provisions in employment law, e.g. protection against dismissal, holiday entitlement and retirement age.

It is of the utmost importance that the application is supported by careful medical documentation, even if it is made by legal representatives and with the support of social services. This is essential for the accurate recognition of the applicant's health problems. If the above-mentioned documents are not available at the time of submission, they will be requested by the administrative staff of the pension offices. They check whether the criteria in the appendix to § 2 of the *Versorgungsmedizin-Verordnung*/"Versorgungsmedizinische Grundsätze" are met. The more detailed the patient's health impairment is described in the doctor's letter, the more accurately the application can be processed. In addition to the transplant and kidney function, additional effects of the underlying disease (e.g. visual impairment in cystinosis, liver dysfunction in ARPKD, hearing impairment in Alport, bronchopulmonary dysplasia in LUTO, cardiac hypertrophy, brain malformations, movement disorders, cognitive impairment, short stature, nutritional and failure to thrive disorders, etc.) should also be explicitly listed. In addition, diseases independent of the kidney disease should be included. A look at the guidelines will help to understand the terminology and concepts familiar to case workers.

The main benefit groups resulting from SGB IX are benefits for medical rehabilitation, including early intervention and support for self-help; participation in working life, including sheltered workshops; maintenance or supplementary benefits; benefits for participation in education and social participation, including assistance benefits, mobility benefits and special aids.

## Care insurance benefits

For the purposes of this book, “vulnerable people” are those who have health-related impairments to their independence or capabilities and who therefore require assistance from others. Such persons must be unable to compensate for or cope with physical, cognitive or mental impairments or health-related burdens or demands independently. The need for care must be permanent, be expected to last for at least six months and meet the criteria of § 15 (§ 14.1 SGB XI).

A kidney transplant alone does not usually lead to a need for long-term care. Instead, the Medical Service of the Health Insurance Funds (MDK) uses an assessment procedure to determine the extent to which a person is able to act independently in defined areas. The modules that are tested include (i) mobility, (ii) cognitive and communicative abilities, (iii) behavioural and psychological problems, (iv) self-care, (v) coping with the demands and stresses of the illness or therapy, and (vi) organisation of everyday life and social contacts.

There are two exceptions to the approach used for adults when determining the level of care for children. Firstly, for children up to the age of 11, a comparison is always made with healthy peers, as children are still developing certain skills. In the case of children with disabilities, the level of care is determined on the basis of the child’s specific needs. The question is therefore whether the child’s ability to care for himself or herself is below the norm for his or her age. Secondly, since healthy infants and toddlers are also dependent on comprehensive care, there is a “natural” need for care regardless of whether there is a complex illness. To take this into account, children under 18 months who need care are classified one level of care higher than adults.

The primary factors that determine the need for care after kidney transplantation in childhood and adolescence are therefore additional impairments associated with syndromic kidney disease. These may include global developmental disorders, associated epilepsy, motor/movement disorders or sensory impairments. In addition, the general challenges associated with kidney disease may also contribute to the level of care. These may include incontinence, the need for tube feeding, complex therapeutic regimens involving frequent medication administration, out-of-home therapeutic services and frequent visits to the doctor, or regular monitoring of bodily functions.

The level of care, which can range from 0 to 5, determines the range of benefits available, including care allowance, care benefits in kind (such as basic care services provided by professional carers), combined benefits (which combine

cash benefits and benefits in kind, including care aids and consumables), and benefits to protect the carer (such as pension and accident insurance for carers).

There are also entitlements to short-term and/or respite care to reduce the burden on family carers. It should be noted that successful kidney transplantation in the absence of a syndromic disorder with developmental delay can significantly reduce and often even eliminate the need for care.

## Summary

Even after a kidney transplant, a person remains chronically ill and severely disabled. The social services provide advice on social rights and help to enforce them. Many services require a medical prescription. Even if the social services provide support in this respect, the taxi licence/transport prescription, rehabilitation application and prescription of medical aids remain activities for which doctors are responsible and which may be relevant to the budget and recourse. Payers often rely on medical reports and expert opinions. The more complete and accurate these are, the more accurate the implementation and the lower the risk of appeals.

## References

- 1 Roters in: Kasseler Kommentar, Sozialversicherungsrecht, SGB V, status: August 2019, Section II marginal number 22.