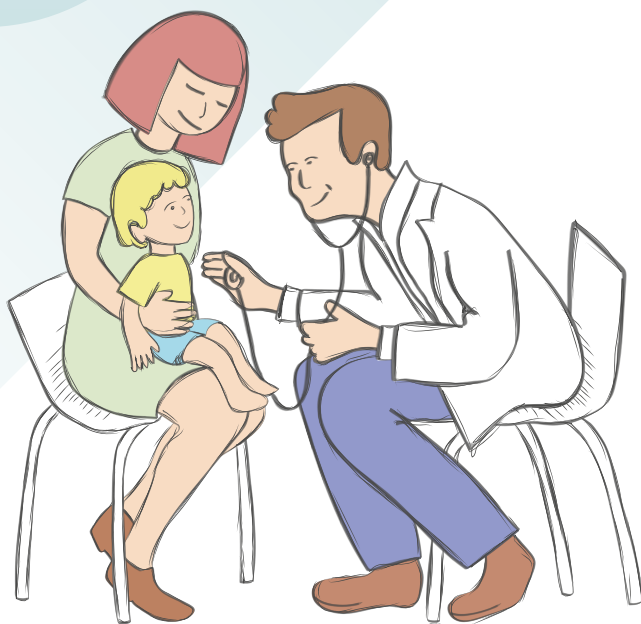


Guide to Social Services for Germany

Guide for assistance **to families**
with a chronically ill child



Preface

Dear Readers,

The Gesellschaft für Jugend- und Familienhilfe e.V. (Association for Youth and Family Assistance), located in Überlingen on Lake Constance, has been providing help to children, adolescents, and their parents throughout Germany on an individual, flexible, residential and non-residential basis since 1994 as a nationally recognized youth welfare provider.

We specialists support and encourage young people in their mental, health, and social development and advise parents and guardians in their child-rearing responsibilities and in managing day-to-day needs.

Families with chronically ill children are particularly burdened and need specific information and support in coping with everyday life, in addition to medical care.

We often witness that the parents themselves as well as the professionals who support them are at a loss and helpless as they confront the many forms of and options for assistance. They wonder where and how they can find options for the support they need.

Together with Albireo, we have thus set out to publish a nationwide guide to social services for families with chronically ill children in order to fill in the gaps.

We very much hope that you will find this social services guide to be a helpful companion.

Yours sincerely,

Karin Merkle
(Executive Management, GJFH e.V.)

Dear Readers,

Albireo is a young, small company dedicated to the research, development, and marketing of drugs for rare diseases.

Shortly after we introduced our first drug for a rare pediatric disease in Germany, we also learned that many families with chronically ill children need guidance in the complex German social services and healthcare system to find and obtain the support that is possible and provided.

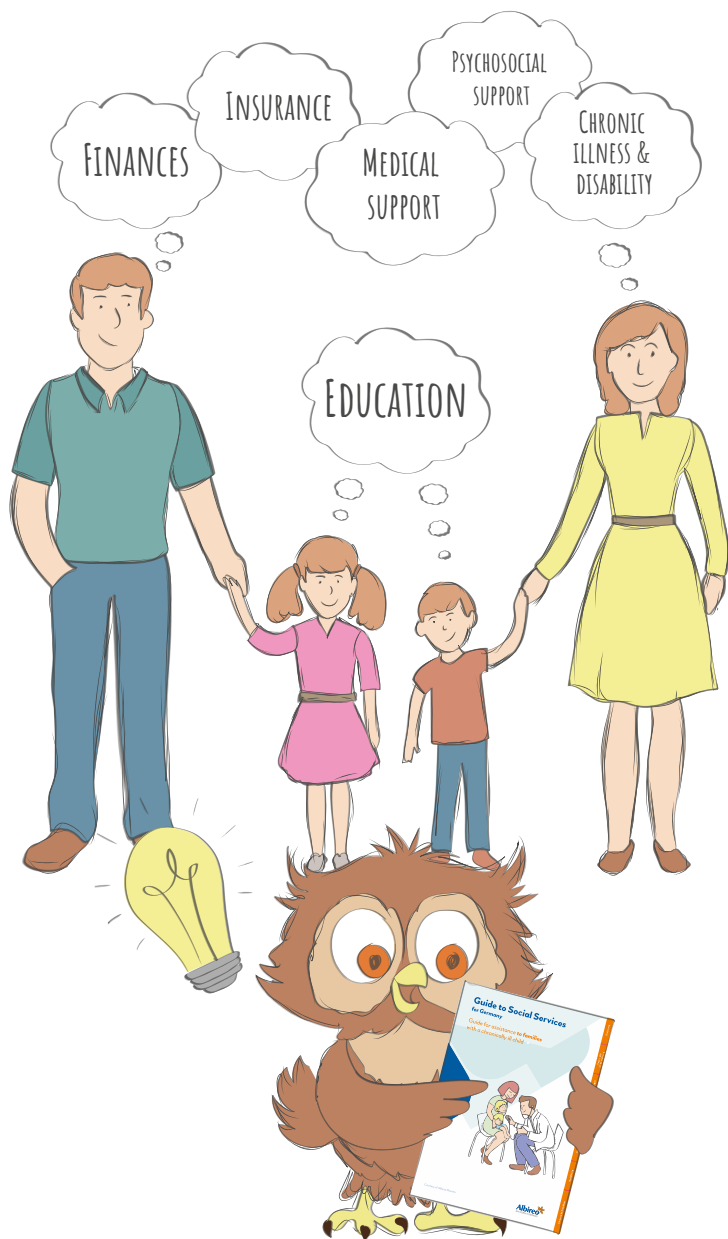
Family members of sick children often do not know about all of the assistance services and support options that are available to them in Germany.

We want to provide help with this brochure, whose contents were kindly compiled by the experienced social workers of GJFH e.V.

We hope that you, dear children, patients, parents, and family members, find a great deal of useful information and support using this guide that make life with a chronic illness easier for you!

With best wishes,

Dr. Michael Jiresch
(General Director, Albireo Germany)



What can this brochure do and what can it not do?

The contents of this brochure were carefully researched. Nonetheless, errors cannot be completely excluded. Sources or laws may change after the publication of this brochure. In this respect, the authors cannot assume liability for the accuracy of the information.

This brochure is for all families, family members, and patients with chronic illnesses, as well as for interested individuals.

1.2 “Chronic illness” and “disability”

What’s what?



1.2.1 Chronic illness

What is a chronic illness?

What exactly is a chronic illness? This is not uniformly defined. Normally, the term “chronic illness” is used to define an illness that is protracted, serious, or cannot be cured.

The German Social Code (SGB) states that a disease is chronic when it constantly necessitates more **services of the healthcare system**.

The Federal Joint Committee (G-BA) states that a person is chronically ill if he/she goes to the doctor at least every 3 months in a year as a result. In addition, one of the following 3 points must apply:

- Need for care (grade 3, 4, 5).
- A degree of disability or reduction in earning capacity of at least 60%.
- Without continuous medical care, life-threatening worsening of the disease, a decrease in life expectancy, or permanent impairment of quality of life is expected.



More information about chronic illnesses is available here:

https://www.aok-bv.de/lexikon/c/index_00275.html

<https://www.g-ba.de/themen/#C>

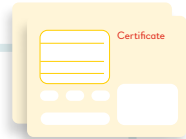


1.2.1 Chronic illness

Who certifies a chronic illness?



Note: Your doctor issues the certificate. You do not need to buy the form! Depending on the disease, the form is valid for 1 year or longer.



You can see a sample of the form here:

— <https://www.praxisformulare.de/muster-55-bescheinigung-einer-schwerwiegenden-chronischen-erkrankung>

1.2.2 Disability

How is a disability defined?

Info:

Degree of disability (DOD) is between 20 and 100.

The German Social Code states that people with a disability:

- have physical, mental, cognitive, or sensory impairments.
- have participated in society with more difficulty for more than 6 months or cannot participate in society at all.
- are considered to be severely disabled if they have a DOD of more than 50.
- can be equated to severely disabled persons under certain conditions if they have a DOD between 30 and 50.



Medical experts determine the degree of a disability and the impacts of the impairment. More information is available here:

— <https://www.rehadat.de/lexikon/Lex-Grad-der-Behinderung-GdB/>

1.2.3 The term “disability”

How is the word “disability” used?

If a family with a chronically ill child seeks support, they often come across the word “disability.” Here, the legal definition is meant. However, it is often not possible to precisely differentiate “disability” and “chronic illness.”

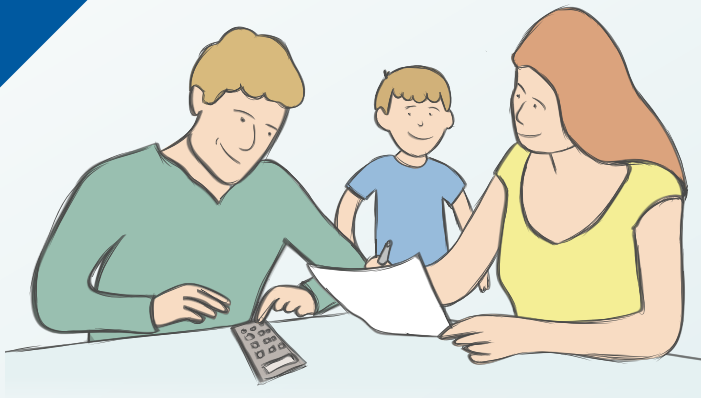
For example: Children with the chronic disease type 1 diabetes do not have any visible disability. However, the amount of therapy that these children need is very high. Therefore the legislature states that they have what is known as a “legally justifiable disability.”

Do not feel excluded or devalued by the word “disability.” The word often also includes chronic illnesses, but it does not only if a legal certificate for a disability is necessary.

Note: The term “disability” is used in this brochure as it is defined in the German Social Code.



Where can I find financial support?



Living with a chronically ill child may also present financial challenges. The support needed may mean that a parent can only work to a limited extent or not at all. The child's care may also necessitate exceptional expenses.

Chapter 2 provides an overview of possible points of contact and assistance.

What services does the state offer?



Which state services can I receive?

– <https://infotool-familie.de/>



Local information center:

– <https://familienportal.de/dynamic/action/familienportal/142486/suche>



Overview of social services:

– <https://www.bmas.de/DE/Soziales/Sozialhilfe/Grundsaeetze-der-Sozialhilfe/grundsaeetze-der-sozialhilfe.html>



We explain how state services work:

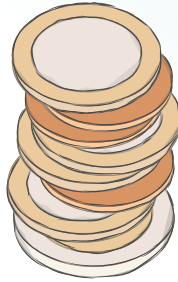
– <https://www.bildungserver.de/staatliche-leistungen-fuerfamilien-1851-de.html>



2.1.1 Employment agency and unemployment benefits

Do I receive support if I lose my job?

Anyone who loses his/her job can apply to the employment office for unemployment benefits:



Information about unemployment benefits, citizen's benefit and other options for support:

<https://www.arbeitsagentur.de/arbeitslos-arbeit-finden>

2.1.2 Job center, education and participation

Anyone who does not receive unemployment benefits can apply for **citizen's benefit** at the job center.

A few facts about citizen's benefit

- Ensures a minimum living income
- **"Supplementation": Apply for citizen's benefit due to a low income**
- **Application: Online or by mail to the job center**



On the employment agency page, you will find more information and your local job center:

<https://www.arbeitsagentur.de/arbeitslos-arbeit-finden/buergergeld>



<https://www.arbeitsagentur.de/arbeitslos-arbeit-finden/buergergeld/finanziell-absichern/einkommen-ergaenzen>

The educational package



An educational package is available for children in families with less money. It is intended to facilitate participation in society.

The educational package is for people who receive a housing benefit or citizen's benefit. For example, meals in daycare, a childcare center or school or costs for a sports club are covered.

- Contact partner:
<https://www.bmas.de/DE/Arbeit/Grundsicherung-Buergergeld/Bildungspaket/Anlaufstellen/anlaufstellen.html>
- Guidance for families with children with a disability or health limitations. Ask your integration assistant.



Single parents

Child support and special support options

For single parents

- Relief payment: Lower taxes
- Allowances for children
- Child support in the event of separation

More information:

<https://familienportal.de/familienportal/familienleistungen/steuerentlastungen/was-sind-freibetraege-fuer-kinder--125198>

<https://familienportal.de/familienportal/familienleistungen/unterhalt>

Child support:

If the children only live with one parent, they are eligible for child support from the other parent.

- **Limited guardianship:** Support by the youth welfare office in the case of conflicts regarding paternity or child support

Information brochure:

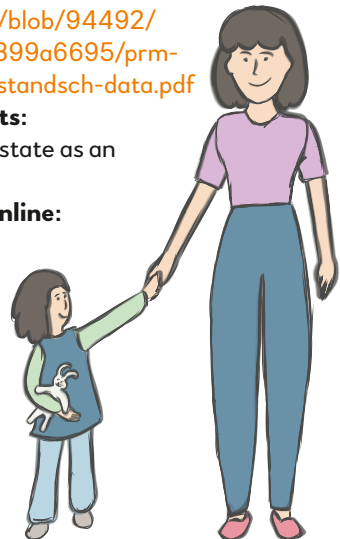
<https://www.bmfsfj.de/resource/blob/94492/c7697366a5bd7f0ca2f14c72399a6695/prm-10481-broschure-die-neue-beistandsch-data.pdf>

- **Advance child support payments:**

Child support is provided by the state as an advance payment.

- **Find your youth welfare office online:**

<https://www.unterstuetzung-die-ankommt.de/de/>



Support for families with children

How long is child benefit paid, in general?



Multilingual information on child benefit for disabled children:

https://bvkm.de/wp-content/uploads/2019/08/2020_mein-kind-ist-behindert_final.pdf



Check here whether you can receive children's allowance for low-income families:

<https://www.arbeitsagentur.de/familie-und-kinder/kinderzuschlag-verstehen/kiz-lotse>



Information on children's allowance:

https://www.arbeitsagentur.de/datei/kiz2-merkblattkinderzuschlag_ba015395.pdf



Who gets parental benefit?

Parental benefit and parental leave

- Submit application if possible by 3 months after birth
- **Basic parental benefit:** 12–14 months
- **Parental benefit Plus (ElterngeldPlus):** 28 months, for example, in the case of part-time work
- **Partnership bonus:**
 - 4 additional months can be claimed per parent
 - with part-time work (25–30 months)
 - for single parents
 - or for couples when parenting is shared jointly



Information about parental benefit:

Parental benefit in simple language:

<https://familienportal.de/familienportal/eltern-geld-und-eltern-geld-plus-in-leichter-sprache-127292>



Informational video:

<https://www.bmfsfj.de/bmfsfj/themen/familie/familienleistungen/elterngeld/elterngeld-73752>

Sibling bonus:

<https://familienportal.de/familienportal/familienleistungen/elterngeld/familiensituation/geschwisterbonus-wie-viel-elterngeld-bekomme-ich-wenn-ich-weitere-kinder-habe--124684>



Apply for parental benefit digitally:

<https://www.elterngeld-digital.de/ams/Elterngeld>



Who can apply for financial assistance for housing?



Information on accessible housing starting on page 33.

https://bvkm.de/wp-content/uploads/2019/08/2020_mein-kind-ist-behindert_final.pdf

Who receives a housing benefit?

- Low-income renters
- People who do not receive any citizen's benefit or welfare

Homeowner benefit:

- People who own their home or apartment

Where can I apply for a housing benefit?

City, community, or district

Note: It is possible to receive housing benefit, children's allowance, and education and participation services at the same time



Subsidized apartment:

- "Public housing"
- Less expensive rent
- Requirement:
Certificate of eligibility for public housing
<https://www.wohnberechtigungsschein.net/>



Support options

Kindergarten fees differ between federal states.

Overview:

<https://www.bildungsserver.de/kita-gebuehren-und-beitragsfreiheit-5674-de.html>



People who receive one of the following services can be exempted from daycare fees:

- Children's allowance
- Citizen's benefit
- Income support
- Welfare
- Services according to the asylum-seeker law
- Housing benefit

Apply for coverage of costs:

- Youth welfare office
- In the event of unemployment: Federal Labor Office



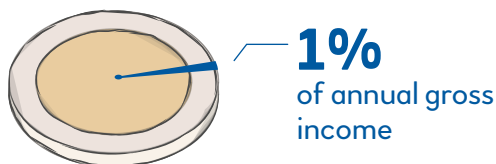
Tip for self-payers: Costs for childcare are "special expenses" in the tax return

In the case of chronic illnesses

You need to send the following to the health insurer for exemption from co-payments:

- “Muster 55” form from the doctor
- Original receipts for co-payments
- Income tax verification (copy)

Limit for payments in the case of exemption:



How long is the exemption valid?

Generally 1 year

Rules for an exemption:

<https://www.verbraucherzentrale.de/wissen/gesundheitspflege/krankenversicherung/zuzahlungen-die-regeln-fuer-eine-befreiung-bei-der-krankenkasse-11108>

Information on co-payments for chronically ill persons:

<https://krankenkassen.net/gesetzliche-krankenversicherung/leistungen-der-gkv-allgemein/chronisch-krank-zuzahlung.html>

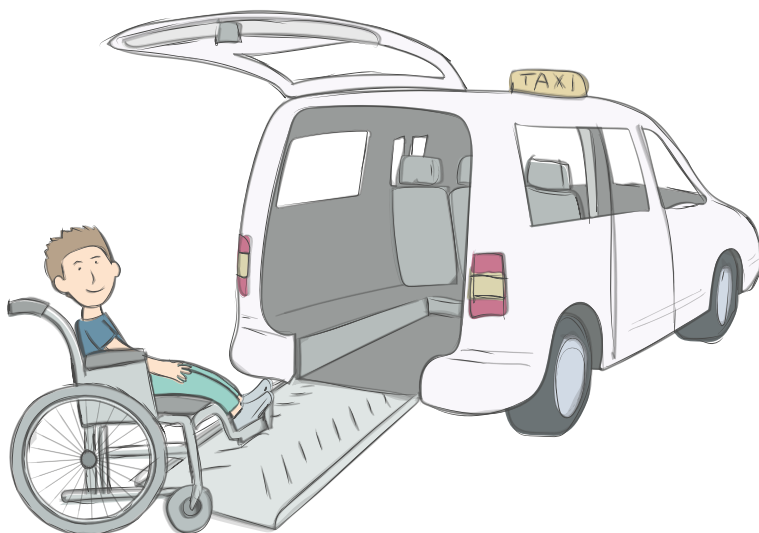


Who pays for medically necessary travel?

You can apply to your health insurer for a reimbursement of the costs of medically necessary travel.

More information about travel reimbursement:

<https://www.bundesgesundheitsministerium.de/fahrkosten.html>



Foundations and support options

Leisure, recreation, and social interaction are important for families with chronically ill children. Support is available here for this:



German Foundation for the Chronically Ill:

Project and networking

– <https://www.dsck.de/startseite>



Overview of foundations

General overview of and search for foundations by region or for individual cases/special topics:

– <https://www.stiftungen.org/startseite.html>



BAG Families and Recreation

Association of non-profit family vacation sites

– <https://bag-familienerholung.de/>



Leisure activities for siblings

Outdoor education leisure activities for siblings:

– <https://carlstiftung.de/baerenstark-ferienfreizeiten/>



Spa treatments with and without children

More information from your family doctor or the Müttergenesungswerk (organization providing rest and recovery options for mothers)

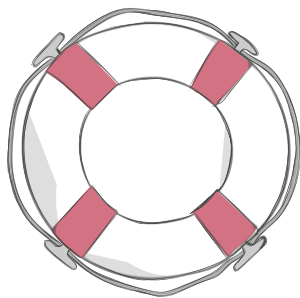
– <https://www.muettergenesungswerk.de/>

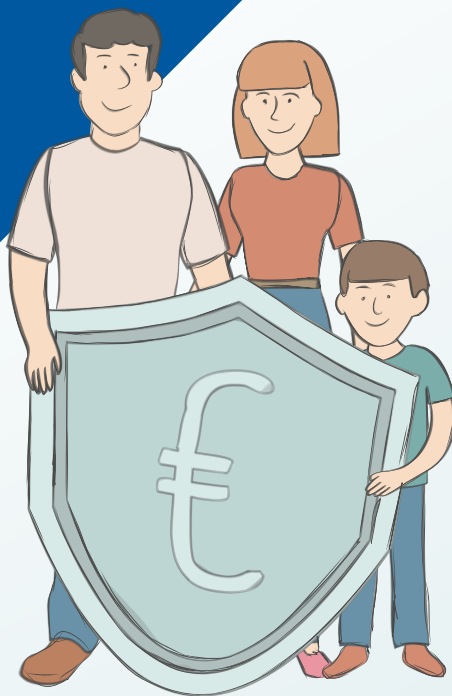
When expenses become too much...

Living with a chronically ill child may be financially difficult. Sometimes bills are forgotten. If this is the case, inquire in the town hall or district administration for “debt counseling.”

The debt counseling service in the town hall or district administration will help with:

- obtaining an overview.
- developing a strategy.





For affected families of a chronically ill child, it is important to safeguard against certain risks, such as the need for care. Although it is not necessarily required to take out insurance, some insurance may be useful in the event of a chronic illness. The insurance that may be useful is described below.

The information here is not comprehensive, since the insurance market is large and continually changing.

Facts on health insurance

- Legally required
- The provider can be freely selected
- It is possible to change providers and it is useful when there is an unsuitable range of services or overly high costs

3.1.1 Private or statutory insurance?



Statutory health insurance (SHI):

Family insurance

Child is co-insured with parents without additional costs

More information:

<https://www.verbraucherzentrale.de/wissen/gesundheit-pflege/krankenversicherung/familienversicherung-in-der-krankenkasse-wer-kostenlos-mit-rein-kommt-28982>



<https://www.verbraucherzentrale.de/wissen/gesundheit-pflege/krankenversicherung/krankenkasse-pflichtversichert-freiwillig-oder-privat-29354>

Private health insurance (PHI):

- More flexible and more services possible
- Generally more expensive

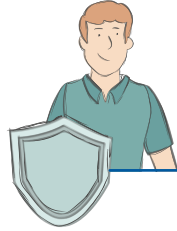
3.1.1 Private or statutory insurance?

Important!

Private insurance for newborns:



Application
no later than
2 months after
birth



Parent with
private insurance
for at least
3 months



Advantages and disadvantages of private insurance:

— <https://www.verbraucherzentrale.de/wissen/gesundheit-pflege/krankenversicherung/private-krankenversicherung-nicht-fuer-jeden-sinnvoll-13884>



— <https://www.verbraucherzentrale.de/wissen/gesundheit-pflege/krankenversicherung/krankenkasse-pflichtversichert-freiwillig-oder-privat-29354>



- In the case of a chronic illness/disability, SHI can have advantages
- In the case of PHI, a pre-existing illness can be assessed as a risk factor
- Caution: High risk premiums as a chronically ill person are possible in the case of PHI

Special rates

Special rates include structured treatment programs (disease management programs (DMP)).

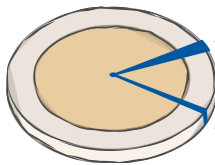
More information about special rates for chronic illness:

<https://krankenassen.net/gesetzliche-krankenversicherung/leistungen-der-gkv-allgemein/spezialtarife-fuer-chronisch-erkrankte.html>



The following applies to statutory health insurers:

- The catalogue of services is always the default!
- Therefore similar benefits in the case of chronic illness
- Co-payment exemption in the case of a certain limit



2%

of the annual gross income

In the case of a serious chronic illness:

1%

of the annual gross income

For more information:

<https://www.bundesgesundheitsministerium.de/themen/krankenversicherung/online-ratgeber-krankenversicherung.html>



Factors for the selection of the person concerned



- Needs of the insured person
- Needs arising from the illness
- Family income

More information, comparisons, tests, and evaluations:

<https://www.krankenkassen.de/krankenkassen-vergleich/>

<https://krankenkassen.net/gesetzliche-krankenversicherung.html>

3.2 General information on supplemental insurance

What is supplemental insurance?

- Is additionally concluded with external providers
- Types of supplemental insurance:
 - Supplemental hospital insurance
 - Hospital daily allowance insurance
 - Daily sickness allowance insurance
 - Outpatient supplemental insurance
 - Supplemental and complementary insurance
 - International travel health insurance

Ask your health insurer which supplemental insurance is useful for you!



In supplemental insurance, children are not automatically covered along with parents!

What is nursing care insurance and who is covered?

- SHI: Everyone automatically receives nursing care insurance
- PHI: You must provide your own nursing care insurance
- Special advantages of supplemental nursing care insurance
 - Example: Daily care allowance insurance which pays for daily rates when the need for care occurs



Children and adolescents who require care are entitled to:

- Benefits of care insurance
- Therapeutic care

More information available at:

<https://www.menschen-pflegen.de/pflegeratgeber/besondere-pflegesituationen/unterstuetzung-fuer-familien-mit-schwerstkranken-und-chronisch-kranken-kindern.html>



Overview of care support centers throughout Germany:

<https://www.zqp.de/beratung-pflege/#/home>

Helpful information for persons with private insurance:

<https://www.compass-pflegeberatung.de/>



Compare supplemental care insurance:

<https://www.check24.de/pflegezusatzversicherung/>



Is liability insurance necessary?

Coverage of damage/injuries to:

- Third-party property
- Other persons

For persons with chronic illnesses or disabilities, liability insurance is particularly useful. Due to the special circumstances, such as a wheelchair, damage can occur more easily to third-party property.

Wheelchair example:

- If the “vehicle” travels at less than 6 km/h, damage is covered by good liability insurance
- One’s own insurance is necessary for wheelchairs with speeds over 6 km/h



Compare liability insurance:

<https://www.check24.de/privathaftpflicht/>

3.5 Accident insurance

Private accident insurance

- Insurance for the mental or physical impacts of an accident (permanent or not)
- No special insurance for chronically ill persons



Statutory accident insurance: Only during work and en route to and from the workplace.



Compare accident insurance:

<https://www.check24.de/unfallversicherung/>

What is term life insurance?

- Term life insurance provides support for surviving family members in the event of death
- An insured sum agreed on beforehand is paid out in the event of death
- Protection for one's own family from financial problems



It can often be difficult to take out term life insurance with a chronic illness.

Here you can learn what you can do in this case:

<https://www.verbraucherzentrale.de/wissen/geld-versicherungen/weitere-versicherungen/lebensversicherungen-schutz-im-todesfall-und-geldanlage-13887>



Compare term life insurance:

<https://www.check24.de/risikolebensversicherung/>



Is legal protection insurance useful in the case of a chronic illness?

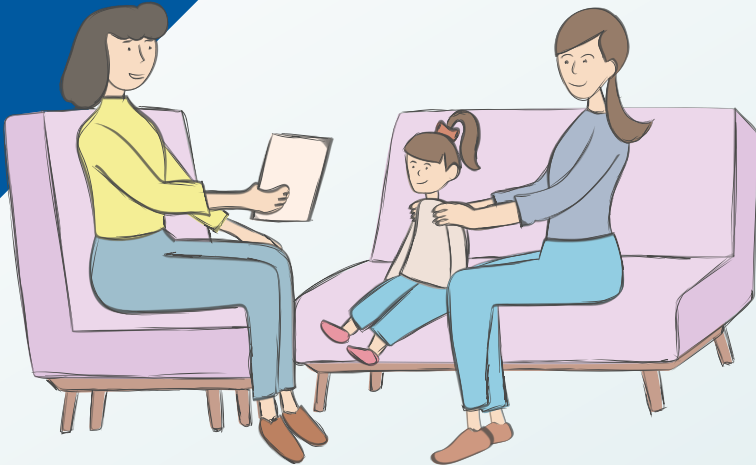
- Useful in the case of chronic illness if another insurance company does not want to provide any benefit
 - Example: Accident insurance company does not want to provide a benefit in the event of a claim

Compare legal protection insurance:

<https://www.check24.de/rechtsschutzversicherung/>



4. Social and psychological support



A stressful time for families frequently begins following the diagnosis of a chronic illness. Life planning or the way in which family life is organized may need to be adapted. Many families need assistance in searching for information, therapy spots, support options, or practical help. There are different points of contact for these various questions.

What is child and youth welfare?

Child and youth welfare refers to help offered by independent and public sponsors. These are defined in the German Social Code by laws and regulations. Sponsors refer to independent cities, the districts, or the federal state. They are responsible for organizing assistance for children and adolescents. The youth welfare office controls this.

The focus is on:

- Children and adolescents
- Young adults up to 27 years of age
- Affected parents

Child and youth welfare services

Child and youth welfare includes:

- Social work
- Help with parenting and support of families
- Daycare for children
- Support for young adults
- Integration assistance for children or adolescents with mental disorders
- Taking children and adolescents into care
- Full and limited guardianship

The procedure for child and youth welfare services:

Parents and adolescents can apply to the relevant youth welfare office for these forms of assistance. Families are entitled to select which services they would like. The youth welfare office pays for the services.

The practical implementation of child and youth welfare services

The assistance or services are then implemented by what are known as “independent sponsors.” These are organizations. Their job is to provide “help for self-help.” This means supporting independence.

Here is an overview of the most important of these sponsors:

- Diakonisches Werk (DW; Protestant charitable organization)
- German Caritas Association (DCV)
- German Red Cross (DRK)
- German Parity Welfare Association (DPWV)
- Workers' Welfare Association (AWO)
- Central Welfare Board of Jews in Germany (ZWST)
- Association of Independent Children's Homes (VPK)



The local youth welfare offices advise on questions about living with children:

<https://familienportal.de/>



Foster families & residential groups

Foster families (section 33 German Social Code 8)

Sometimes parents cannot care for their child themselves. They can file an application with the youth welfare office for a foster family. The parents and the child may decide together when selecting a foster family.

Residential groups (section 34 German Social Code 8)

Young people can also move into an assisted living community. In these communities

- 6–10 young people live
- 3–5 trained educational specialists look after the young people
- There are various core special needs areas
- Parents are involved
- There are generally costs incurred for the parents

Follow-up care

What is known as “follow-up care” can help when children return to the family.

- Follow-up care is paid for by the health insurer
- For chronically or severely ill children and adolescents under age 14 (in special cases up to age 18)
- Requirement: Assistance to allow children to come home or with organizing treatment in the family’s own home.



More information:

<https://www.bundesgesundheitsministerium.de/service/begriffe-von-a-z/s/sozialmedizinische-nachsorge-fuer-schwerkranke-kinder.html>

Non-residential services

Information centers (section 28 German Social Code VIII)

- Free consultations for children, adolescents, and parents for personal, family, and medical questions
- Therapeutic help

Addresses and telephone numbers: Notices in youth welfare offices, pediatricians' offices, and libraries

Non-residential assistance by the youth welfare office

- **Sociopedagogical family support/non-residential support:** Support for families at home regarding parenting questions or, for example, with regard to visits to authorities or contacts with kindergartens or schools. The application is submitted to the youth welfare office.
- **Social educational parenting support:** An education professional supports young people themselves.
- **Day group:** In a day group, children receive care during the day on weekdays. Each child also receives individual support.
- **Social group work:** Social groups help with developmental difficulties and children learn social competences there.

Help for families with small children

- Time period: pregnancy to 3 years of age
- Assistance from various areas

More information on early intervention is available here:

<https://www.elternsein.info/>



4.3 Advisory services

4.3.1 Child guidance centers

See 4.1.2. Non-residential services in the chapter “Assistance for youths and families”

Points of contact for families



Interacting with families who also have chronically ill children can help.



More information:

- German Consortium of Self-Help Groups:
<https://www.dag-shg.de/>
- **Children's network** <https://www.kindernetzwerk.de/>
- **German Federal Center for Health Education – Information for parents with sick children:**
<https://www.kindergesundheit-info.de/themen/entwicklung/behinderung/wegweiser-behinderung/>



An ombudsman can provide independent information, advice, and mediation to families in contact with the public or independent sponsors of child and youth welfare services. This service is free of charge.

– <https://ombudschaft-jugendhilfe.de/>



Family centers

<https://www.bundesverband-familienzentren.de> –



Multigenerational houses

– <https://www.mehrgenerationenhaeuser.de/>



Counseling for siblings

The siblings of chronically ill children may also suffer as a result of the situation.



Services for siblings:

Family Ties Foundation (Stiftung Familienbande):

– <https://www.stiftung-familienbande.de/>

“Lebenshilfe”:

<https://www.lebenshilfe.de/informieren/familie/geschwister> —



Contact partners by telephone

Sometimes a conversation helps with worries and distress.

Oskar telephone help line

Using the free Oskar telephone help line, you can talk to trained counselors about the diagnosis of an incurable disease in your child, terminal care, or grief.

Number: **0800 8888 4711**



Pastoral care helpline

A pastoral care helpline is a service of the Protestant and Catholic church. Available around the clock:

0800 111 0 111 and **0800 111 0 222**

More information and points of contact:

<https://familienportal.de/familienportal/lebenslagen/krise-und-konflikt/krisetelefone-anlaufstellen/krisentelefone-und-anlaufstellen-in-notlagen-124544>



4.3.4 Finding independent therapists

Where can I find support?

Therapists support you and your family in living with a chronic illness. Selecting appropriate therapy is very important.



Finding a therapist online:

<https://www.therapie.de/therapeutensuche/>

<https://www.therapieplatz-jetzt.de/>

– <https://www.116117.de/de/aerztlicher-bereitschaftsdienst.php>



In Bavaria, the coordination center for psychotherapy assists in finding open therapy spots.

– <https://www.kvb.de/service/patienten/koordinationsstelle-psychotherapie/>

Telephone: 0921 88099 40410

Hours: Mon.-Thu. 9:00 a.m.-5:00 p.m.,

Fri. 9:00 a.m.-1:00 p.m.

4.3.5 Support for migrants and refugees

Assistance in the case of chronic illness or disability

There is special protection in Germany for chronically ill and disabled persons who had to leave their homelands.

They are entitled to

- housing that is as accessible as possible.
- medical care.
- provisioning with aids, such as a wheelchair.

This is in a directive of the EU known as the “EU reception directive for asylum seekers (2013/33/EU).” Some of this assistance does not work well in Germany. Finding support is therefore sometimes difficult.



More information is available here:

— <https://www.familienratgeber.de/beratung-hilfe/weitere-hilfen/fluechtlinge-behinderung.php>



Additional points of contact:

• Caritas provides consultations in person or online with regard to **migration and flight**:

— <https://www.caritas.de/hilfeundberatung/onlineberatung/migration/start>



• **The German Association of Psychosocial Centers for Refugees and Victims of Torture (BAFF) supports the psychosocial and therapeutic care of refugees:**

— <https://www.baff-zentren.org/>



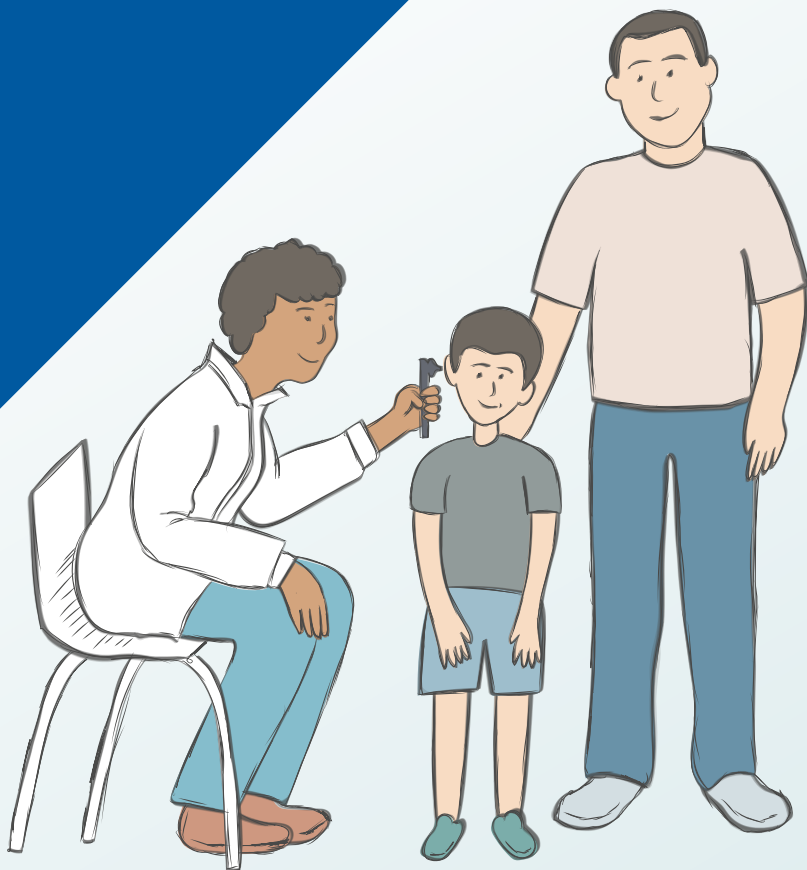
• **The Federal Agency for Political Information (Bundeszentrale für politische Aufklärung) provides information about points of contact and health care for refugees:**

— <https://infodienst.bzga.de/migration-flucht-und-gesundheit/weiterfuehrende-links/anlaufstellen-und-gesundheitsversorgung-fuer-gefluechtete/>

• **Legal topics regarding migration and refugees:**

— https://www.bamf.de/DE/Themen/themen_node.html





5.1 Medical facilities

5.1.1 Pediatricians

General information & finding a doctor

<https://www.kinderaerzte-im-netz.de/startseite/>



Your pediatrician may refer you to:

- a **social pediatric center** (see 5.1.5)
- a **specialist doctor** (see 5.1.6)
- and/or a **specialist clinic**

He/she will issue you a **referral** and the health insurer will cover the costs.

5.1.2 Medical on-call service

It is possible to call the **medical on-call service**:

- Assistance in evaluating whether there is an emergency
- Telephone number **116117**
- Free of charge (no area code; from Germany)



**Life-threatening situations
or serious accidents: Dial 112!**

Pay attention to dental health

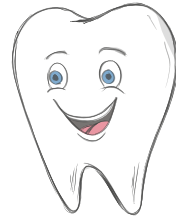
Diseased teeth cause pain.
Regular dental visits are important.
Not every practice is geared for people with a disability.



The Intakt website provides comprehensive information about dental visits:

- Cost coverage for general anesthesia
- Practices for people with a disability

<https://community.intakt.info/t/zahnaerztliche-versorgung/7069>



How do I find a clinic?

List of all pediatric clinics and pediatric hospitals and departments in Germany on the website of the German Society of Pediatric and Adolescent Medicine (DGKJ):

<https://www.dgkj.de/veroeffentlichungen/kinderkliniken>



What is a social pediatric center?

Centers for children and adolescents with a chronic disease or who are suspected to have a chronic disease.

If your child has **behavioral problems, psychological disorders, developmental disorders or disabilities**, your doctor can refer you to an SPC.

Advantages of an SPC:

- **Close collaboration** with private-practice doctors, therapists, and facilities of the healthcare system
- **Into adolescence**
- **Family is involved**



Find an SPC:

<https://www.dgspj.de/institution/sozialpaediatrische-zentren/>

5.1.6 Specialists

How do I find a specialist?

Specialists are doctors who **specialize in certain diseases**. Your doctor may send you to a specialist.



To find a specialist:

<https://www.dgkj.de/eltern/spezialisten-portraits>

Self-help and support



Children's network

Knowledge and self-help for affected parents and networking with doctors, policies, and service providers.

— <https://www.kindernetzwerk.de/>



EURORDIS:

Association of patient organizations and persons who advocate for people with rare diseases in Europe

— <https://www.eurordis.org/de/>

ACHSE:

Alliance of self-help organizations for people with chronic rare diseases and their family members

— https://www.achse-online.de/de/die_achse/achse_ev.php



For children and adolescents

Rehabilitation is also available for children. Take the **special needs of young people** into account when selecting rehabilitation!



Pediatric and adolescent rehabilitation on the web:

— <https://www.kinder-und-jugendreha-im-netz.de/startseite/>



German pension insurance:

— https://www.deutsche-rentenversicherung.de/DRV/DE/Reha/Medizinische-Reha/Reha-fuer-Kinder-und-Jugendliche/reha-fuer-kinder-und-jugendliche_node.html

Pediatric rehabilitation centers in Germany:

— <https://www.dgspj.de/category/kinder--rehazentren/>



5.2.1 Co-payment of medications

What does the health insurer reimburse?

People with statutory health insurance

Prescription medications:

- Are covered for children and adolescents by the health insurer
- No co-payment until age 18

Non-prescription medications:

- Normally must be paid for out of pocket
- Exception for children under age 12 and adolescents with developmental disorders:
 - Prescribed by the doctor
 - **Medications on this list:**



<https://www.bundesgesundheitsministerium.de/themen/krankenversicherung/arzneimittelversorgung/arzneimittel.html>

People with private insurance

Payment for medications: People with private insurance initially pay out of pocket. For reimbursement of costs, send the pharmacy bill to your health insurer.

Medicinal products are reimbursed if they

- are **prescribed** by the doctor
- are recognized by **conventional medicine**
- are purchased in a **pharmacy**
- or, if there is no conventional medical preparation, proven preparations from **alternative medicine**.

Where do I buy my medications?

Medications can be purchased in

- pharmacies,
- online pharmacies,
- or directly from the doctor, in exceptional cases.



Finding a pharmacy

Online

<https://www.aponet.de/>

Emergency pharmacy:

<https://www.aponet.de/service/notdienstapotheker-finden.html>



Mobile phone

Telephone call or SMS to **22833**
(no area code; 69 cents/minute
or SMS)

Landline

0800 00 22 8 33
(free, around the clock)



Where can wheelchairs, insulin pumps & prosthetic devices be obtained?

Aids:

Devices or objects that

- safeguard against disabilities,
- help in the case of disabilities,
- support rehabilitation.



The statutory health insurers pay for aids.
Information on applying for cost coverage:

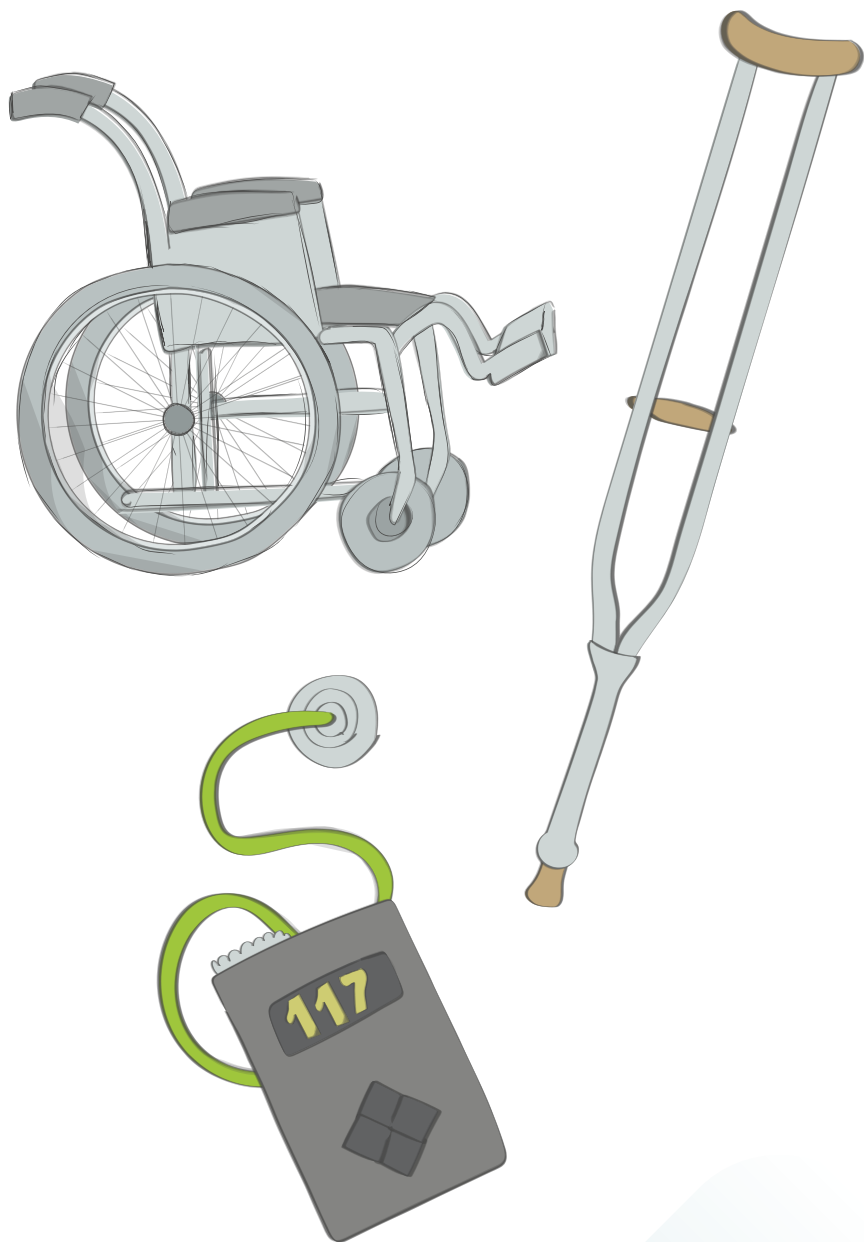


<https://www.lebenshilfe.de/informieren/familie/wie-komme-ich-zu-meinen-hilfsmitteln>
and



<https://www.verbraucherzentrale.de/wissen/gesundheitspflege/krankenversicherung/hilfsmittel-beantragen-wie-geht-das-richtig-6895>
and

<https://www.verbraucherzentrale.de/wissen/gesundheitspflege/krankenversicherung/hilfsmittel-wer-traegt-welche-kosten-6900>



Dietary changes in chronic diseases

A switch or adaptation of the diet may support therapy.
Your health insurer pays in part for nutritional counseling if the disease

- was **caused by diet** or
- a **dietary change is useful**.

Your doctor will issue you an **attestation of need**.



"Nutritionist" is not a protected term. Look for reputable offerings. Nutritionists are:

- **Ecotrophologists**,
- **Dietitians**,
- **Medical nutrition specialists** with additional qualification.

Health insurers pay only for nutritionists who do not advertise or sell products.



You can find qualified experts at:
Professional Association of Ecotrophology
(VDOe Berufsverband Oecotrophologie e. V.):
<https://www.vdoe.de/>



German Nutrition Society
(Deutsche Gesellschaft für Ernährung e. V.):
<https://www.dge.de/>



German Society of Qualified Nutrition Therapists and Nutritionists (QUETHEB e. V.):
<https://www.quetheb.de/>



German Association of Dietitians
(Verband der Diätassistenten):
<https://www.vdd.de/diaetassistenten-suche>

Information from the Federal Agency for Nutrition (Bundeszentrale für Ernährung):
<https://www.bzfe.de/ernaehrung>





Kindergartens for disabled children:

- Special education kindergarten: the costs are covered by the sponsor of the integration assistance
- Inclusive kindergarten: normal costs

Assistance/medical care:

- Personal assistance: Costs are covered by the sponsor of the integration assistance
- Medical care: Health insurer covers home health care



- Children and adolescents with a disability can receive integration assistance and child and youth welfare services
- Your region, the districts (depending on federal state), or the youth welfare office is responsible.
- Statutory period of 14 days: thereafter the first place approached pays



6.2.1 Chronic illnesses and school

Be aware of the following when selecting a school:

- Appropriate school type
- How many students is a teacher or educator responsible for?
- Class size
- Academic discipline
- Core area of special needs
- Accessibility
- Distance and the journey to school

A chronic illness can have effects on day-to-day school life. Decide together with your child which school he/she would like to and is able to attend.

Possible problems for teachers:

- Middle ground between vigilance and excessive attention
- Knowledge of symptoms and treatment (such as for type 1 diabetes)
- Adaptation of the performance assessment (such as in physical education in the case of severe obesity)
- Legal barriers (such as "May I give the medication?")
- Handling behavioral particularities (such as tics)
- Response in crisis situations (such as epileptic seizures)
- Practical problems (medication supply, making arrangements for field trips)

Possible questions for parents:

- Does my child have to go to school?
- Is school attendance or schooling currently possible?
- Can I leave my children at home?
- Which school is right for my child?
- What support will I receive for school attendance?

Is school compulsory or possible at all?



Compulsory school attendance is legally applicable in Germany:

- Mandatory from age 6 to age 18
- The right to school, education, and inclusion



Chronically ill children must attend school and also be included there!

Is schooling currently possible?

- Depending on the disease condition or progression
- Excused absences: In general up to three days verbally, thereafter up to 10 days in writing (be aware of school regulations!)
- Longer absence: Sick leave/doctor's certificate

What happens if my child has an unexcused absence?

- The school reports the absence to the education authority after 10 days
- Fines may then result
- Community service for the student in the event of non-payment

Information on truancy:

<https://www.bussgeld-info.de/schulverweigerung-bussgeld/#massnahmen-der-schule>



What should we be aware of when selecting a school?

How do I know whether the school is appropriate?

People who can help:

- Family doctor or clinic
- Therapists
- Integration assistants
- Early intervention centers
- Information centers
- Youth welfare office and family and social workers
- Current school



Note: You are entitled to freely select the type of school for your child with a disability.

What assistance is there for my child?

- Talk to the school about whether day-to-day school life can be improved. Possible contact persons: Director, class teacher, school social worker, school psychologist, or parents' association.
- If there are no options, look for a more appropriate school.

Special schools

- “Schools for sick children” (specializing in illness)
- Special schools
- Special needs schools with certain areas of focus

6.2.2.1 General links for selecting a school in view of illnesses



Education server:

— <https://www.bildungsserver.de/schule-fuer-krank-11278-de.html>



**Association of Special Needs Education
(Verband Sonderpädagogik e.V.):**

— <https://pbkr.info/schulen-fuer-krank-in-deutschland>

6.2.2.2 Federal level



<https://www.bildungsserver.de/schule-fuer-krank-11278-de.html#Bundesebene>

Links to special schools in the federal states



Hospital schools in each federal state:

— <https://www.schups.org/category/klinikschulen/>

Schools for sick children in each federal state:

— <https://pbkr.info/schulen-fuer-krank-in-deutschland>



Other websites for individual federal states:



Baden-Württemberg

Special educational and support centers with boarding school in Baden-Württemberg:

— https://www.schule-bw.de/faecher-und-schularten/schularten/sonderpaedagogische-bildung/sonderpaedagogische-bildungs-und-beratungszentren-sbbz/sbbz_internat/karte



Bavaria

Schools for sick children in Bavaria:

— <https://www.km.bayern.de/ministerium/schule-und-ausbildung/schulsuche.html>

Teaching materials on the subject of children with cancer:

— https://www.km.bayern.de/download/185_krebskrankelinder_internet_032012.pdf



Other websites for individual federal states:



Berlin & Brandenburg

— <https://bildungsserver.berlin-brandenburg.de/schule/hilfe-und-beratung/schule-und-krankheit/klinikschulen-be>

School and chronic illness in Berlin-Brandenburg:

https://bildungsserver.berlin-brandenburg.de/fileadmin/bbb/schule/Hilfe_und_Beratung/Schule_und_Krankheit/pdf/Schule_und_Krankheit.pdf



Bremen

Gesundheit Nord – Hospital Association Bremen:
School for sick children:

— <https://www.gesundheitnord.de/kbm/diagnostische-und-therapeutische-bereiche/schule-fuer-krank-kinder.html>



Hamburg

Educational and counseling center, pedagogy in illness/
autism:

<https://www.hamburg.de/bsb/bbz/>



Hessen

State welfare association, Hessen:

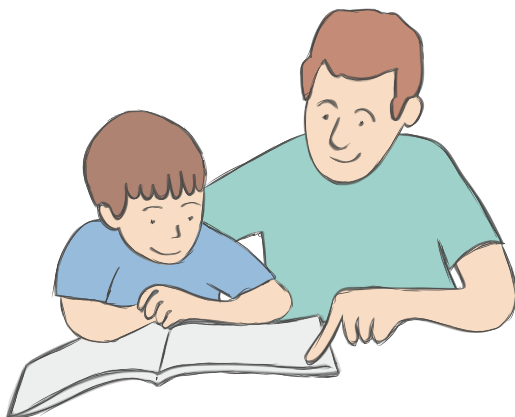
Sick students:

<https://www.lwv-hessen.de/foerderung-schule/krank-schuelerinnen-schueler.html>



Individual assistance in school for children with disabilities

A classroom aide can support your child in class and during breaks.



Information on classroom assistance:

<https://fachverband-schulbegleitung.de/schulbegleitung/>



<https://www.familienratgeber.de/lebensphasen/kindergarten-schule/schulbegleitung.php>

6.3.1 Vocational preparatory measures and rehabilitation training



The Federal Labor Office provides information to persons with disabilities or chronic illnesses on vocational preparation and selecting training:

- It helps determine skills, interests, and preferences
- It provides a medical-psychological assessment

Your relevant office:

<https://web.arbeitsagentur.de/portal/metasuche/suche/dienststellen>

Vocational preparation courses (VPC) help

- In discovering professions and companies
- In the case of discontinued training
- In catching up on school-leaving qualifications: Basic school-leaving certificate (Hauptschulabschluss) or equivalent certificate



More information:

<https://www.arbeitsagentur.de/bildung/ausbildung/berufsvorbereitende-bildungsmassnahme>

The Federal Labor Office also helps in finding a **training position or appropriate job:**

<https://www.arbeitsagentur.de/menschen-mit-behinderungen/berufliche-rehabilitation>



Special support for people with disabilities

Vocational training institutes (VTI) are designed to fit the needs of the disabled and offer:

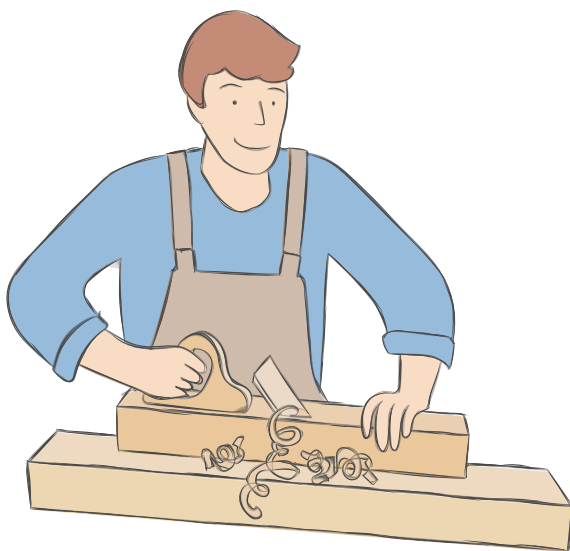
- Vocational school
- Training centers
- Housing



You work with companies on site. Young people can inquire with the Labor Office about the VTI.

More information is available at:

<https://www.bagbbw.de/berufsbildungswerke/>





7. Chronic illness



Federal Participation Act (BTHG)

The BTHG regulates the access to numerous services and support for people with chronic illnesses and disabilities.

Assessment of needs

The needs assessment procedure starts with an application. Which services are needed are determined together with the affected person. A “providing sponsor” coordinates the measures (such as region, health insurer, pension insurance institute).



Regulations and access to the support differ from federal state to federal state.

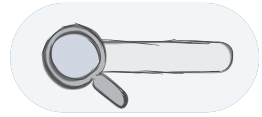


Overview of the BTHG:

— <https://www.lebenshilfe.de/informieren/familie/eingliederungshilfe-und-das-bundesteilhabegesetz>

<https://www.bmas.de/DE/Soziales/Teilhabe-und-Inklusion/Rehabilitation-und-Teilhabe/bundesteilhabegesetz.html>





Additional links regarding the BTHG:

EUTB information centers:

<https://www.teilhabeberatung.de/>



Social participation for children and adolescents:

<https://www.soziale-teilhabe-kiju.lwl.org/de/>



Occupational participation and education:

<https://www.rehadat-adressen.de/adressen/>

<https://www.arbeitsagentur.de/menschen-mit-behinderungen/berufliche-rehabilitation>



Offices of integration and inclusion:

<https://www.bih.de/integrationsaemter/kontakt/>

Welfare association VdK Deutschland e.V.:

<https://www.vdk.de/deutschland/>



Advantages of the disability ID card

The disability ID card offers access to services and benefits for persons with a disability. It should therefore be applied for in any case.



Equal status can be applied for at the relevant department of the Federal Labor Office.

Here you will find your relevant department:

<https://web.arbeitsagentur.de/portal/metasuche/suche/dienststellen>



Equal status offers certain rights:

- Special protection against dismissal
- Assistance in professional life
- Advice and support through integration services
- Employment incentives for employers

More information about the disability ID card:

<https://www.schwerbehindertenausweis.de/>



How can I apply for care services?

The degree of care can be applied for via the relevant health insurer or nursing care insurance fund. Based on a care level, a person is entitled to financial support. The following steps are important for this:

- File an application for care services with your or your child's nursing care insurance fund.
- You can submit the application in writing or via telephone.
- The health insurance medical service provides an appraisal. This is known as a nursing care assessment.
- Obtain independent advice before you file the application for care services.



Disability ID card

Video with explanations on the care assessment by the health insurance medical service:

<https://www.medizinischerdienst.de/versicherte/pflegebegutachtung/>



At or above a certain degree of care, you can hire a caregiver.

At or above a degree of care of 2, a care allowance can be obtained if the care service is performed personally.

Learn more here:

<https://www.bundesgesundheitsministerium.de/pflegegeld.html>



If you care for your child yourself, your taxable income is reduced by the flat-rate care amount.

For more information:

<https://familienportal.de/familienportal/familienleistungen/steuerentlastungen/wird-die-pflege-von-angehoerigen-bei-der-steuer-beruecksichtigt--125218>



For people whose primary residence is in Bavaria, there is additionally the option of applying for what is known as a state care allowance (Landespflegegeld) at a care level of 2 or higher. It is 1000 Euros per year.

The application forms can be found here:

<https://www.lfp.bayern.de/landespflegegeld/>



Support in the care of a child

If you need support, time off, or a break in the care of a child, the family relief service is available to you.

Advice and information is available at “Lebenshilfe”:

<https://www.lebenshilfe.de/>



7.5 Additional important links



More information on family support services:

<https://www.familienratgeber.de/beratung-hilfe/hilfen-alltag/familienunterstuetzender-dienst.php>



Guide to living with a disability:

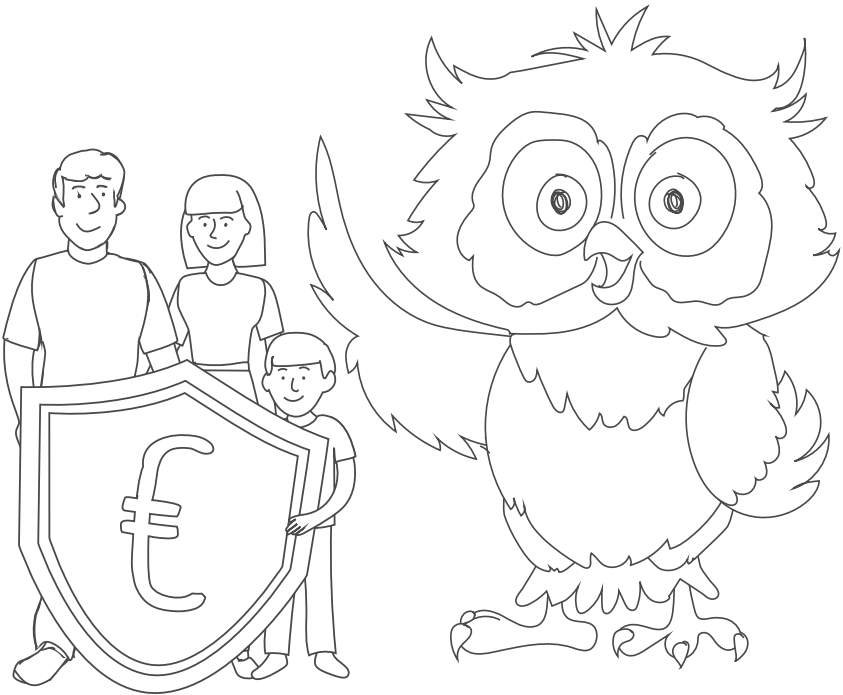
https://www.einfach-teilhabe.de/DE/AS/Home/alltagssprache_node.html

The brochure “My child is disabled – an overview of available help” is available in several languages:

<https://bvkm.de/ratgeber/mein-kind-ist-behindert-diese-hilfen-gibt-es-in-mehreren-sprachen/>



Would you like to color?



Courtesy of



DE-NP-23-00032