

Information Brochure about Stroke

– for those affected and their relatives

Also available
digitally as a PDF

[www.dsg-info.de/
Informationsbroschuere-
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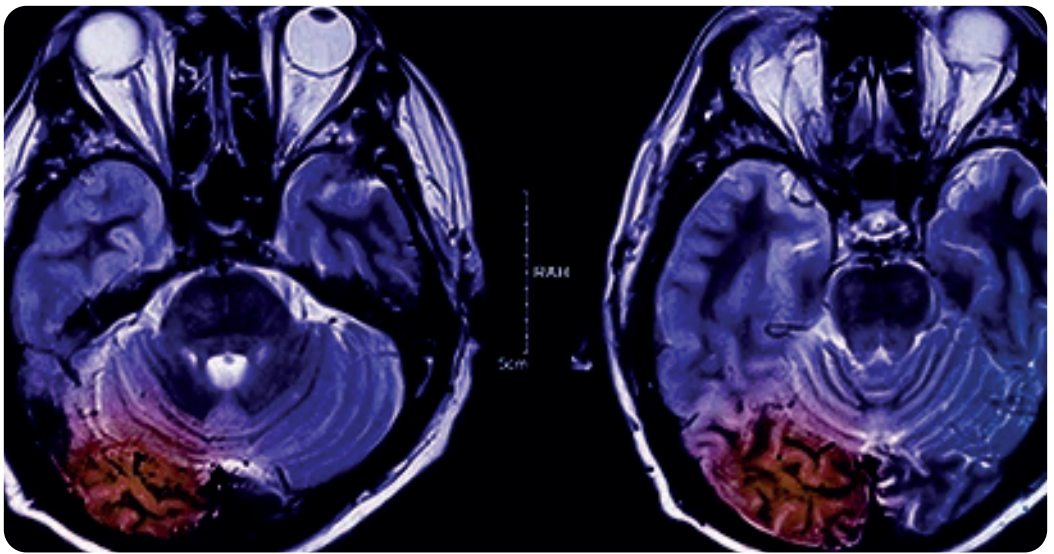
In collaboration with



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Dear patients, relatives, and interested readers,

This brochure aims to provide you with vital information about stroke, put together by the experts at the Deutsche Schlaganfall-Gesellschaft (DSG) [German Stroke Society] and the Stiftung Deutsche Schlaganfall-Hilfe [German Stroke Foundation]. By having a better understanding of the disease, we hope that affected patients can achieve a greater quality of life. Confidence is key in this regard. We place particular value on follow-up care in stroke, as well as on prevention of further stroke events (termed 'secondary prevention'). This brochure should not be relied on as a substitute for inperson discussions with your treatment team but rather should help to complement and reinforce the information provided during those consultations. To get the most educational value from this brochure, we recommend marking out the sections which are most relevant for you. The information contained in this brochure is based on the Guidelines for Secondary Prevention following Ischaemic Stroke and Transitory Ischaemic Attack (TIA)^{1,2}, the Patient Guidelines for Acute Treatment of Stroke³ from the DSG [German Stroke Society] and the Deutsche Gesellschaft für Neurologie [German Society of Neurology], and the Guidelines on Cerebral Haemorrhage⁴. To help you to understand the medical terminology you are likely to encounter, we have explained the common terms below.



1. Definition - Stroke

A stroke means that there has been a critical impairment to blood flow to the brain, which is typically experienced as a sudden loss of function. We tend to differentiate between two types:

- Cerebral infarct and TIA: Impaired blood flow due to a blockage in an artery (approx. 85%)
- Cerebral haemorrhage: A 'bleed on the brain', due to an artery in the brain having a leak (approx. 15 %)

Sometimes when an artery gets blocked, the blood flow can be re-stored quickly entirely on its own. In these cases, the neurological deficits only last for a short period (from a few minutes up to max. 24 hours). These episodes are called TIAs (transitory ischaemic attacks). Following a

TIA, there is a significantly increased risk of a 'complete' stroke occurring. For this reason, a TIA is still considered a medical emergency, despite its neurological effects being limited.

2. Typical signs of stroke

Impaired function which occurs suddenly, such as:

- Paralysis of an arm and/or leg, both on one side of the body
- Loss of sensation in an arm and/or leg, both on one side of the body
- Difficulty with speech, or inability to speak
- Visual disturbance: missing areas in the visual field; double vision
- Severe headache with sudden onset

3. Important modifiable risk factors for stroke

- High blood pressure (arterial hypertension)
- Smoking
- Issues with cholesterol/fat metabolism (particularly high LDL cholesterol)
- Atrial fibrillation (heart rhythm disorder)
- Diabetes mellitus
- Being overweight
- Lack of exercise
- Excess alcohol intake
- Oestrogen-containing oral contraceptive
- Use of illicit drugs (e.g. cocaine, amphetamine)

There are also other risk factors which the treatment team will look into if they are suspected.

4. The most important causes of stroke

a) Cerebral infarct/TIA (ischaemic stroke)

Ischaemic stroke has a variety of causes. We divide these into 3 main groups:

- Atherosclerosis (calcification of the blood vessels) where this affects the large arteries in the neck or at the base of the skull (macroangiopathy = disease of the large blood vessels)

- Disease of smaller arteries in the brain (microangiopathy = disease of the small blood vessels)
- A blood clot, formed in the heart, becomes dislodged and is transported to the brain (cardiac embolism)

There are further causes which are rare, predominantly affecting younger patients (under 60 years). These include:

- Injury to the blood vessel wall of arteries supplying the brain (dissection)
- Rheumatic inflammation of the vessels (vasculitis)
- Coagulation disorders with an increased tendency to spontaneous clot formation (thrombophilia)
- Formed clots passing through a hole in the heart (= paradoxical embolism); the most common hole in the heart is called a PFO (persistent foramen ovale). A PFO is a heart defect which occurs very frequently, but which does not cause any issues in most cases.

In approx. 1 in 5 patients no cause for the stroke will be identified. These are termed 'cryptogenic' strokes (cryptogenic = 'hidden'). In this case, the term 'ESUS' is used (Embolic Stroke of Unknown Source)

b) Cerebral haemorrhage

The most significant causes and factors which provoke cerebral haemorrhage (with no trauma) are:

- High blood pressure: this can lead to areas of weakness in the vessel walls which develops silently over time, associated with an increased risk of rupture (rupture = rip or tear in a vessel). Instances of severe blood pressure elevation (hypertensive crisis) can also lead to cerebral haemorrhage.
- Small-vessel disease as a result of protein deposition (amyloid angiopathy), which is associated with an increased risk of vessel rupture due to a weakened vessel wall
- Abnormal structure of the arteries (aneurysm, vascular malformation) which is associated with an increased risk of vessel rupture due to a weakened vessel wall
- Coagulation disorders with a tendency to increased bleeding; many different diseases and medications can cause this
- Thrombosis (clot formation) in the cerebral veins with bleeding due to congestion (blood becoming 'backed up')

There are also rare causes of cerebral haemorrhage (e.g. rheumatic inflammation of vessels, coagulation disorders) which can be further investigated if there is a justified suspicion they may be playing a role.

5. Immediate measures to take in case of stroke

Both stroke and TIA are medical emergencies which require immediate treatment.

- Call 112 (the emergency services), or have someone make the call
- Keep the affected person awake by talking to them; actively try to prevent them from falling asleep
- Remove any dentures and ensure their airway is clear
- Do not give anything to eat or drink
- Provide any important information to the ambulance service (see point no. 6)

6. Important information for the ambulance service

- How long have the symptoms been present? If the exact time of onset is unknown: when was the affected person last known to be asymptomatic (last seen 'normal' for them)?
- Current medications, particularly any bloodthinners (see also no. 10b)
- Contact information including telephone/mobile number of the relative

7. Treatment in the hospital

Treatment for acute stroke consists of the following steps:

- Confirming the diagnosis and differentiating from other disease which can look like stroke ('stroke mimics').
- Imaging of the head, possibly incl. imaging of the vessels (CT or MRI) and blood tests
- Acute treatment (if indicated):
Restoration of blood flow using 'thrombolysis' (medications used to dissolve blood clots) and/or 'thrombectomy' (physical removal of a blood clot using a microcatheter)
- Further acute treatment in the stroke unit, or if necessary, in the ICU. This includes the following:
 - Close observation of clinical signs and using monitoring machines
 - Early initiation of rehabilitation measures
 - Determination of the cause using specific investigations
 - Initiation of measures to prevent early complications of stroke, and to stop further stroke events occurring (secondary prevention)
 - Organization of further treatment, rehabilitation, and appropriate aftercare

8. Stroke Units

a) Definition:

A Stroke Unit (SU) is a ward this specially equipped to treat patients affected by stroke. SU treatments are based on the following principles:

- multidisciplinary team approach (see also no. 8b)
- Dedicated treatment spaces
- Close clinical monitoring
- Machines and monitors for observation
- Procedure followed as per binding quality standards and established treatment plans

b) The SU team:

The multidisciplinary team in the SU is made up of the following specialists:

- Medical team: The doctors on the medical team are generally neurologists. Some SUs are led by internal medicine doctors with specialist neurology expertise
- Specially-trained nursing staff
- Physiotherapists
- Speech therapists
- Occupational therapists
- Social services colleagues

Further specialists, e.g. neuropsychology, are involved under specific circumstances. The tightknit team works together with regular communication on a daily basis.

9. Discharge management and social services

To ensure a smooth transition into outpatient care or further care in a rehabilitation facility, a so called 'discharge management' system is used. This encompasses the following:

- Planning rehabilitation treatment, where needed.
- Referral, if needed, for outpatient treatment (such as physiotherapy, occupational therapy, and speech therapy), for medical aids (such as walking aids), and home nursing or short-term care for a transition period.
- Ensuring information is relayed correctly to the provider of ongoing care (usually the GP) in the form of a discharge letter, including a medication plan.

Further advice can be provided by the treatment team or the hospital's social services department.

10. Secondary prevention: Goals and Treatment Measures

After a stroke or TIA, the risk of a further stroke occurring is increased. This risk can be mitigated by initiated targeted treatment measures. This includes the following:

a) Ensuring a healthy lifestyle

(see also no. 11)

b) Reducing formation of blood clots:

- A standard medication often used is: Aspirin 1 x 100 mg once daily
- Alternatively to aspirin: Clopidogrel 1 x 75 mg once daily. In certain situations, this can also be used in combination with aspirin, but almost always for a limited time period only. Please be aware of this limited time period when receiving treatment with a combination of both aspirin and clopidogrel.
- Very rarely, alternatives to aspirin or clopidogrel can be used: Ticagrelor 2 x 90 mg
- Direct-acting oral anticoagulants (DOAC): These are used when a more intensive blood-thinning effect is required. The most common reason for using a DOAC is atrial fibrillation. Preparations:
 - Apixaban (e.g. Eliquis®): To be taken as per prescribed dose
 - Dabigatran (e.g. Pradaxa®): To be taken as per prescribed dose
 - Edoxaban (e.g. Lixiana®): To be taken as per prescribed dose
 - Rivaroxaban (e.g. Xarelto®): To be taken as per prescribed dose
 - Phenprocoumon (e.g. Marcumar®, Falithrom®): Dosing is patient-specific and is guided by regular blood testing of coagulation values.

c) Reducing blood pressure:

Blood pressure should be reduced following a stroke or TIA to achieve long-term values of less than 140/90 mmHg. In this regard, the following should be kept in mind:

- Taking medications: generally you will need to take a medication. Ensure that you take medications regularly.
- Self-measurements: Check your own blood pressure values regularly and note down the recordings. Important: the blood pressure should be taken when at rest – sit down and relax for a few minutes before taking measurements. Then, take two measurements around 3 minutes apart, and note down the 2nd value.
- Nutrition and lifestyle measures: These contribute to reductions in blood pressure. These include: low-salt, low-fat, and high-vitamin diet; avoiding alcohol; and regular stamina-based exercise

d) Lowering cholesterol:

After an ischemic stroke, medication is usually needed to lower cholesterol. One of the main goals is to reduce the levels of LDL cholesterol ('bad' cholesterol). A common target is to lower LDLs to below 70 mg/dl (< 1.8 mmol/l) or to achieve a 50% reduction from the baseline value. Depending on the individual risk profile, even

lower target values may be used.

Ask your treatment team about your individualised LDL target.

- Statins: The main medications used for this purpose, taken once daily (preferably at night). The dose is adjusted for the individual patient and is based on the reduction in LDL achieved and how well the medication is tolerated. The most commonly used medications are:
 - atorvastatin, rosuvastatin, and simvastatin.
- Further medications: there are a range of other medications which can be used in addition to statins: e.g. ezetimibe, bempedoic acid, PCSK9-inhibitors.
- Nutrition and lifestyle measures: A healthy diet and doing regular stamina-based exercise contribute to lowering LDLs.

e) Treatment for diabetes mellitus:

This also involves a combination of lifestyle measures and using medications.

- HbA1c: This is the 'long-term' blood sugar value, an indicator of how successful treatment is. The target value depends on the patient's age, any other illnesses, and the risk of having hypoglycaemia (blood sugar that is too low).
 - Aged under 65: HbA1c target value $\leq 7.0\%$ (6.5-7 %)

- Aged 65 and above: HbA1c target value $\leq 7.5\%$ (6.5-7.5 %)
- In the elderly: Target value $< 8\%$

f) Adherence to medications:

In any cases where medications are taken, it is important that they are taken regularly as per the prescribed medication plan.

11. Recommendations for diet and lifestyle modification

- Physical activity: The optimal level of exercise each week is either 150 minutes of moderate-intensity physical activity (e.g. brisk walking or cycling) or 75 minutes of intense physical exercise (e.g. jogging). It is recommended to increase exercise levels gradually. In case of significant disability (e.g. paralysis), appropriate options for exercise can be assessed as part of rehabilitation treatments.
- Nutrition: It is particularly recommended to follow a Mediterranean diet, with regular intake of seafood, whilst avoiding salt, saturated fats, red meat and processed meats (e.g. sausages). It is also recommended to increase intake of fruit and vegetables (ideally: 5 portions per day – one portion is the amount which fits onto the palm of the hand). In case

- of hypertension (high blood pressure), we recommend reducing salt intake.
- Alcohol: Avoid alcohol - at least 2 days per week should be alcohol-free. The following limits apply with regards to alcohol intake:
 - Women: max. 0.25 L beer or 50 ml wine per day
 - Men: max. 0.5 L beer or 100 ml wine per day
- Smoking: Stop smoking or at least reduce smoking to an absolute minimum. Nicotine-replacement products such as nicotine patches and services offerings supporting to quit smoking (www.rauchfrei-info.de or www.anbieter-raucherberatung.de) can be helpful. Simply changing over to e-cigarettes is not enough.
- Avoiding excessive heat: This can trigger a stroke in at-risk individuals. Take care to ensure you keep cool and drink plenty of fluids.



12. Rehabilitation

Even despite the best possible treatments, it is not uncommon for functional deficits to remain following a stroke (e.g. paralysis, difficulty with speech, difficulty swallowing). This is why rehabilitation is needed. The goal of rehabilitation treatments is to obtain the best possible recovery of affected neurological functions, with a return of ability to perform day-to-day activities and improved quality of life. In Germany, rehabilitation is divided into three phases (as per the Bundesarbeitsgemeinschaft für Rehabilitation (BAR) [Federal Association for Rehabilitation]).

- Phase A: Acute in-hospital treatment (no rehabilitation)
- Phase B: There are severe deficits with a significant impairment to (or complete lack of) a patient's ability to engage in rehabilitation, with a need for high-intensity medical and nursing treatment.
- Phase C: The patient is now able to engage in rehabilitation but continues to have a high degree of need for nursing support and medical treatments.
- Phase D: The patient is largely independent in the activities of daily living, but still has some need for support. Often patients are discharged from hospital by the time

they reach phase D. Treatment in this phase can be provided on an outpatient or inpatient basis.

- Phase E: Specific medical rehabilitation, with focus on return to work/activity - usually provided as an additional treatment following completion of the standard rehabilitation phase.
- Phase F: Long-term care to support preservation of function in specialist facilities (not rehabilitation).

Where there is a good response to treatment, patients can progress to the next phase of rehabilitation. For more elderly patients, the alternative of geriatric rehabilitation can be considered. The treatment team will recommend the most appropriate rehabilitation for you.

13. Stroke after-care

A stroke is a complex, chronic illness. Despite successful treatment in the acute phase and in rehabilitation, it often results in complex, long-term impairments which require after-care on an outpatient basis. Many of these impairments can be mitigated by appropriate follow-up treatment as an outpatient. The goal is to ensure the highest possible quality of life, and participation in the activities of life enjoyed prior to the stroke occurring.

In the best case, your continued care should be determined on the basis of close collaboration between your neurologist and your GP. Discuss any issues you are having currently with your doctors so that your further treatment can be adjusted appropriately. You can prepare for your doctor's appointments by filling out the Post-Stroke-Checkliste [post-stroke checklist] (see no. 16), used around the globe. This helps your treatment team to address the main issues you are having. Possible symptoms and issues may include:

- Paralysis and impaired sensation
- Spastic movement disorders
- Unstable gait, limited mobility and falls
- Communication disorders
- Difficulty swallowing
- Visual disturbance
- Persistent tiredness/fatigue
- Attention and concentration disorders, cognitive impairment, and dementia
- Seizure disorders/epilepsy
- Depression and anxiety disorders
- Changes in personality
- Pain
- Continence problems (affecting bladder/bowel)
- Impairment of social activity, e.g. with relatives and friends
- Incapacity for work / Disability (Occupational disability)
- Impaired ability to drive (see also no. 14)

14. Ability to drive

A stroke can significantly impair the ability to drive a vehicle. Depending on the individual's risk profile for a recurrence of stroke, patients are generally not cleared for driving a vehicle for a period of 1-6 months after the event. After this period has passed, fitness to drive must also be assessed based on any residual physical deficit or mental impairment, and the patient's ability to compensate for these. Please ask your neurologist or GP for advice in this regard. Special regulations apply to commercial drivers and drivers working in passenger transport (group 2 vehicles: HGVs, buses). Further details can be found in a brochure published by the Stiftung Deutsche Schlaganfall [German Stroke Foundation] and the Begutachtungsleitlinie zur Kraftfahrreignung [Guidelines for Assessment of Fitness to Drive] by the Bundesanstalt für Straßenwesen (BASt) [Federal Highway Research Institute].



<https://www.schlaganfall-hilfe.de/de/service/publikationen/publikation/did/autofahren-nach-schlaganfall>



<https://www.bast.de/DE/Verkehrssicherheit/Fachthemen/U1-BLL/BLL-Download.html>

15. Important measures in case of severe, lasting disability:

- **Application for recognition of severe disability:** For applications, contact the responsible Versorgungsamt [Pension Office]. Assessment of the Grad der Behinderung (GdB) [level of disability] is generally based on the existing medical reports. In some cases, however, medical assessment by an expert may be necessary. A GdB [level of disability] of 50 or higher is officially classified as 'severe disability'.
- **Application for recognition of a 'Pflegegrad' [care level]:** In the event of foreseeable and permanent impairment lasting more than six months, you should apply for a Pflegegrad [care level]. A Pflegegrad [care level] is assigned on the basis of an expert assessment, which usually takes place during a home visit.
 - If no Pflegegrad [care level] has been assigned yet, an initial application has to be submitted (§ 33 SGB XI [Section 33 German Social Act XI]). It is sufficient to send an informal letter to the insurance provider responsible for providing long-term care, or to notify them by telephone/online.
 - You can get advice on the subject of long-term care needs and the available support services at any time by contacting the insurance provider responsible for care, or by contacting an independent Pflegestützpunkt/ Pflegeberatungsstelle [care advice services point].
 - If a Pflegegrad [care level] has already been assigned, an application for Höherstufung [increased level] can be submitted to the insurance provider responsible for care.
- **Application for 'Haushaltshilfe' [home care]:** If a Pflegegrad [care level] has already been assigned, it is possible to apply the Entlastungsbetrag (§45b SGB XI) [Relief Amount as per Section 45b Social Act XI] to finance care provided in the home. If a Pflegegrad [care level] has not yet been assigned, it is still possible in some cases to have help provided in the home by means of a Verordnung von Übergangspflege (§ 39e SGB V) [prescription for transitional care as per Section 39e Social Act V].

16. Important contacts:

- You can get advice free-of-charge from your insurance provider for healthcare or nursing care.

- Support from the Stiftung Deutsche Schlaganfall
[German Stroke Foundation]

www.schlaganfall-hilfe.de

Tel: 05241 9770-0



- Patientenservice der kassenärztlichen Bundesvereinigung
[Patient Service of the National Association of Statutory
Health Insurance Physicians]

Tel. 116117 or

www.116117.de



- Ergänzende unabhängige Teilhabeberatung (EUTB)
[Supplementary Independent Participation Counseling]

www.teilhabeberatung.de

Tel: 030 284 09-139, -140

E-Mail: fachstelle@teilhabeberatung.de



- Regionale Pflegeberatungsstellen
[Regional Care Advice Points]

www.zqp.de/beratung-pflege

E-Mail: info@zqp.de



- Post-Stroke-Checkliste (PSC)
[post-stroke checklist]:

**[https://www.world-stroke.org/assets/
downloads/psc-gemany-version-wso-
livery-05-20-13.pdf](https://www.world-stroke.org/assets/downloads/psc-gemany-version-wso-livery-05-20-13.pdf)**



Literature

1 https://dnvp9c1uo2095.cloudfront.net/wp-content/uploads/2022/07/030133_LL_Sekunda%CC%88rprophylaxe_Teil-1_2022_final_korr.pdf



2 https://dnvp9c1uo2095.cloudfront.net/cms-content/030143_LL_Se-kunda%CC%88rprophylaxe_Teil2_2022_V1.1_1670949892924.pdf



3 https://register.awmf.org/assets/guidelines/030-046p_S2e_Akuttherapie-des-ischae-mischen-Schlagan-falls_2022-11-verlaengert.pdf



4 https://dnvp9c1uo2095.cloudfront.net/cms-content/0_030-002l_S2k_Behandlung-von-spontanen-intrazere-bralen-Blutungen_2022-03-verlaengert_1708601961438.pdf

