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Guideline for the management of neurogenic bowel dysfunction in spinal cord injury/disease

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INTRODUCTION: Almost all people with spinal cord injury/disease (SCI/D) suffer from neurogenic bowel dysfunction (NBD), with a considerable impact on quality of life. The Association of the Scientific Medical Societies in Germany (AWMF e.V.) guideline for NBD in SCI/D aims to provide practice-oriented support for the care of patients with NBD resulting from congenital or acquired SCI/D. The guideline describes the diagnosis and bowel management of NBD in people with SCI/D. Thus, treatment processes in acute medical care and rehabilitation as well as for lifelong aftercare are presented.

METHODS: The present guideline was developed under the leadership of the German-speaking Medical Society for Paraplegiology in a multiprofessional interdisciplinary guideline team. To exceed the level of expert recommendations, consensus was reached within the framework of a structured nominal group process in defined steps under neutral moderation considering the criteria of the German guideline development instrument (DELBI).

RESULTS: Individual bowel management must be developed on the basis of an adequate diagnosis and considering the different lesion types. Due to the multifactorial influenceability of the intestine and the individual neurological deficit, a simple to-do checklist is not effective. Various and complex bowel management programmes are the basis of the treatment of NBD.

CONCLUSIONS: Guidelines can only be successful in so far as they are applied in everyday life. Of course, the selection and application of the measures described must always take into consideration the individual situation of the person concerned, and the correct application is always a prerequisite for success.

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INTRODUCTION

In most cases, spinal cord injury/disease (SCI/D) is associated with neurogenic bowel dysfunction (NBD). If left untreated, the effects of NBD can lead to serious health consequences. Shame and fear due to a lack of bowel control can lead to social isolation. It is, therefore, crucial to recognise and analyse the neurological deficits in bowel function caused by SCI/D and the multifactorial influence on this system.

Despite the many activities of our professional society on this topic, such as workshops, specialised further training courses to become a “neurogenic bowel expert” and in-house training courses, the practical implementation in everyday clinical practice falls far short of our expectations. Feedback from the interprofessional teams of the paraplegic centres points to a deficit of practically oriented guidelines with clear recommendations for action. Since, in addition to doctors, nursing staff in the paraplegic centres in particular accompany the adjustment to a regulated and continent bowel management, it was necessary to create a comprehensible, German-language practical instruction manual.

At the time of guideline development (2018–2019), no guidelines on bowel management in SCI patients existed worldwide with an evidence level above that of expert opinion. The most detailed guidelines were from MASCIP (Multidisciplinary Association of

Spinal Cord Injured Professionals, [1]) from the UK and ACI (Agency for Clinical Innovation, [2]) from Australia. Neither guideline provides an explanation of guideline development or evidence-based graduations of recommendations. In this respect, we saw the need for the development of a guideline based on a structured consensus process and adapted to the German conditions.

The aim of the guideline is to compile the current state of knowledge on the definition and diagnosis of NBD as well as on bowel management to ensure the competent treatment of patients with NBD to prevent complications and thus positively influence the quality of life of those affected. This guideline aims to provide practice-oriented support for the care of patients with NBD.

We have summarised the individual implementation of all the findings regarding anamnesis and bowel function diagnostics in the context of bowel management. Bowel management refers to the entire range of activities that help a person with SCI/D achieve regular, planned and time-limited bowel evacuation with sufficient stool volume and adequate stool consistency; to maintain health and well-being; and to avoid complications and unplanned defecations. Bowel management is a process that includes assessment, individual planning and implementation of interventions considering individual influencing factors, assessment of

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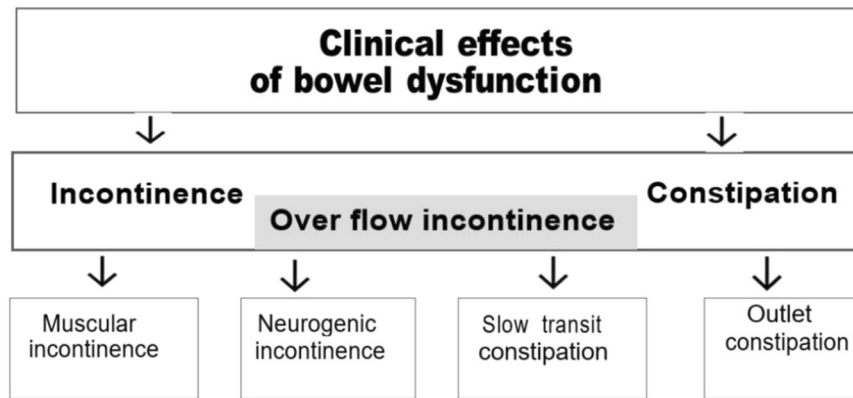


Fig. 1 Leading clinical symptoms of neurogenic bowel dysfunction in people with SCI/D.

outcomes and evaluation. Successful bowel management always requires multiprofessional cooperation between different occupational groups (interdisciplinary teams).

METHODS

The present guideline was developed under the leadership of the German-speaking Medical Society for Paraplegiology e.V. (Deutschsprachige Medizinische Gesellschaft für Paraplegiologie e.V. (DMGP e.V.)).

Experts from the fields of paraplegiology, proctology, visceral surgery, neuro-urology, gastroenterology, health care and nursing as well as nursing science and dieticians/medical nutritionists worked together in a multiprofessional interdisciplinary guideline team (the “Bowel Dysfunction Guideline Group” – BDGG).

A systematic literature search was conducted in the databases PubMed, Science direct, Cochrane, CINAHL. The search terms were neurogenic bowel dysfunction, neurogenic bowel and spinal cord, neurogenic bowel and multiple sclerosis, neurogenic bowel and meningomyelocele/spina bifida, bowel management, constipation and spinal cord, fecal incontinence and spinal cord. The analysis of this literature search served as the basis for this guideline. We proved the grey literature for SCIRE project and existing guidelines (MASCIP, ACI, PVA).

The BDGG identified relevant areas of focus and met several times to develop draft recommendations. Each recommendation was discussed under relevant clinical considerations to facilitate the application of the knowledge. Subsequently, the recommendations developed by the BDGG were discussed in a face-to-face meeting and the final recommendations were voted on separately. Finally, the draft guideline were submitted to the representatives (mandates holders) of the professional societies of the Association of the Scientific Medical Societies (AWMF) involved in the guideline for voting in their boards as a first external review. These had the opportunity to assess and comment on the draft in this development phase.

During 5 guideline committee meetings, consensus was reached within the framework of a structured nominal group process in defined steps under neutral moderation. In the guideline development process, the criteria of the German guideline development instrument (DELBI) [3] were applied. Therefore, the present guideline is not only an expert opinion, but a consensus-based guideline.

After the first external review, the consensus process and prior to submission and publication of the now consented guideline at the AWMF, the second external review was conducted by all members of the DMGP. The members had 4 weeks to comment on the guideline.

RESULTS AND RECOMMENDATIONS

The pathophysiological features of NBD are disturbed sensory function and motility and limited-to-absent reflex control of bowel voiding and continence.

NBD in SCI/D is caused by varying levels of damage to the spinal cord or cauda equina [4]. Changes in gastrointestinal functions after SCI/D depend on clinical appearance at the level of the lesion, the completeness of the injury and the time since the onset of SCI/D. Of crucial clinical importance are the changes in the

motility of the upper and lower gastrointestinal tract, peristalsis, whether the ability to empty the rectum is maintained and whether the anal closure mechanism is functioning. In terms of timing and clinical course, the changes in the gastrointestinal tract after SCI/D can be divided into three phases, with the phases merging smoothly into one another.

Definitions of typical changes in neurogenic bowel dysfunction such as faecal incontinence, constipation, transit constipation or outflow obstruction can be found in Supplementary Material 1.

A detailed description of the typical phasic sequence of neurogenic bowel dysfunction can be found in Supplementary Material 2 (see Fig. 1).

DIAGNOSTICS

Basic diagnostics

Anamnesis (e.g., stool quantity and consistency, stool frequency, perception of the “need to evacuate”, triggering defecation through digital stimulation, voiding duration, timing of defecation, diet, medication, faecal incontinence, unsuccessful attempts at voiding).

Stool observation using the Bristol stool scale (Supplementary File 3).

Assessment of the abdomen with palpation and auscultation.

Anorectal examination:

- Inspection of the perianal region, including pelvic floor assessment to evaluate the skin condition and identify proctological diseases, e.g., fissures/anal tags/perianal thromboses/deformities.
- Sensitivity testing.
- Perianal and deep anal sensitivity, as well as sphincter tone at rest and after voluntary contraction, are examined, assessed and documented in digital rectal examinations (International Standards of Neurological Classification of Spinal Cord Injury (ISNCSCI); Digital rectal examination scoring system (DRESS Score) [5]).
- Anal reflex and bulbocavernosus reflex testing.
- Examination of the ampulla.

Assessments: NBD-Score [6], ISCoS Basis Data Set [7], ISCoS Extended Data Set [8].

Recommendation 1: The medical history and the assessment of anal sphincter tone should be the essential aspects of the initial diagnosis.

Level of evidence: expert consensus (100%).

Advanced diagnostics for neurogenic bowel dysfunction (including stool protocol, feeding and drinking protocol, abdominal sonography, proctoscopy and colonoscopy as well as other imaging procedures) are carried out according to the clinical, individual view of the situation.

Bowel management

The overall goal of bowel management is to achieve secondary continence with regular and sufficient bowel emptying within an individually acceptable time frame and at the right time according to the patient's agenda. Bowel management is a cyclical process.

Recommendation 2: The bowel voiding rhythm, the voiding technique and the use of laxatives and aids should be determined for the establishment of bowel management.

Level of evidence: expert consensus (100%).

Recommendation 3: Continence, emptying rhythm, defecation time and subjective patient satisfaction should be assessed for the evaluation of bowel management.

Level of evidence: expert consensus (100%).

Comparison of the lesions

The following table compares the disorders and symptoms of complete lesions (AIS Grade A/ASIA Impairment Scale) [9] of the upper and lower motor neurons (schematic, see Table 1). In the case of incomplete paralysis, these symptoms also apply in principle; however, these lesions show variable expression with partially preserved sensitivity and motor function. In addition, the possible use of conservative interventions and their combinations with increasing invasiveness after spinal shock has subsided is presented, simplified and differentiated according to lesion type.

The so-called "therapy pyramid" (see Fig. 2) shows a possible escalation of therapy for neurogenic bowel dysfunction, which is widely used in international scientific literature [10].

Recommendation 4: The algorithm should provide the basis for the development of initial bowel management. The adjustment of bowel management should be oriented towards success (continence and voiding rhythm) and should be determined on an individual basis.

Level of evidence: expert consensus (100%).

Recommendation 5: Ideally, bowel evacuation should be planned after a meal (gastrocolic response).

Level of evidence: expert consensus (100%).

Recommendation 6: An rectum check should be performed after defecation to verify complete evacuation.

Level of evidence: expert consensus (100%).

Recommendation 7: A change in bowel management should only be made after sufficient observation (3-5 evacuations/week) (exception: acute interventions).

Level of evidence: expert consensus (100%).

Conservative methods of bowel management

In addition to nutritional management [11], rectal emptying techniques and physical measures constitute the conservative part of bowel management.

Recommendation 8: A regular diet, sufficient fluid intake (1500–2000 ml/day) and intake of dietary fibre (up to 30 g/day, soluble and insoluble) should be the basis of the dietary recommendations.

Level of evidence: expert consensus (100%).

Bowel evacuation techniques

The following measures are presented without ranking. Contraindications must be considered. Correct execution according to professional instructions is obligatory. Disposable gloves are necessary for all rectal procedures. It is advisable to empty the bladder before emptying the bowels. The procedures are to be performed by the patient or a caregiver.

Increasing abdominal pressure by using still innervated abdominal muscles (change in sitting position (bending the upper body forward, pressing the arms or legs into the abdomen, pulling the knees in, using an abdominal bandage or coughing)).

Monitoring/checking the ampullae, i.e., digital palpation of the rectal ampulla to determine the filling status before and after emptying.

Table 1. Algorithm for bowel management, comparison of disorders and symptoms in complete upper and lower motor neuron lesions.

Lesion of the upper motor neuron	Lesion of the lower motor neuron
Upper Motor Neuron Lesion (UMNL)	Lower Motor Neuron Lesion (LMNL)
"Reflexive bowel"	"Areflexive bowel"
Pathophysiology	
Lesion above the conus medullaris, sacral reflex centre is intact	Lesion of sacral segments of the conus medullaris and/or damage to the sacral nerve roots
Clinical symptoms	
Stool transport disorder	
Altered perianal sensation	
Defecation disorder Faecal incontinence (overflow or reflex incontinence)	Defecation disorder Faecal incontinence ("passive leakage")
Increased tone of the pelvic floor muscles	Decreased tone of the pelvic floor muscles
Increased tone of the sphincter ani externus	Absence of tone of the sphincter ani externus
Intact bulbocavernosus reflex	Absent bulbocavernosus reflex
Intact anal reflex	Absent anal reflex
Clinical consequences	
Bowel emptying by rectal stimulation possible	Bowel emptying by rectal stimulation not possible
Goals of bowel management	
Bowel emptying every 2nd day	Bowel emptying 1–2 times daily
Softer stool consistency, 3–4 (Bristol stool scale)	Harder stool consistency, 2–3 (Bristol stool scale)
Therapy	
High-fibre diet, adequate fluid intake, exercise, relaxation	
Utilise gastrocolic response (purging after meal)	
Colonic massage	
Digital stimulation	
Rectal emptying reflex positive: - CO ₂ ; Glycerine, Bisacodyl Suppository	
Digital evacuation	
Rectum check (rectum empty?) approx. 10 min after the last stool evacuation	
Influencing stool consistency (stool modulation) Bulking agents and/or osmotically active, long-term laxatives (macrogols, lactulose)	
Micro-enema, enema	
Transanal Irrigation	

Dilating the anal canal to release the sphincter spasm or to trigger the voiding reflex.

Anus and perineum tapping, i.e., stimulation of bowel evacuation by applying external stimuli for reflex evacuation.

Digital evacuation of the rectal ampulla with the finger by the patient or caregiver.

Enema (Lift vertical enema, high enema) Instillation of water at body temperature or ready-made enema solution for retrograde irrigation of the rectum and the left colon.

Administration of micro enemas/enemas (ready-made solutions) The enema provides a chemical and/or physical stimulus that causes peristalsis to be stimulated and the stool in the rectum to be softened.

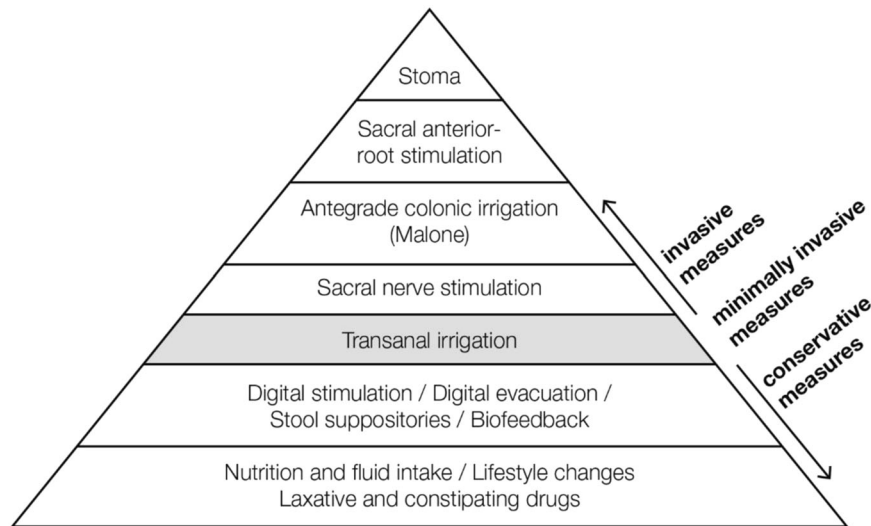


Fig. 2 Therapy pyramid for neurogenic bowel dysfunction (modified from [10]).

Anal Irrigation: Triggering of the voiding reflex as well as the recto-anal inhibition reflex by introducing an individually determined amount of water by means of a rectal catheter (balloon or cone catheter). Irrigation can be performed by gravity or by manual or electric pumping system. Competent and repeated instruction in the handling and handling as well as adequate troubleshooting are prerequisites for successful application [10].

Digital stimulation by circular movement above the anal sphincter with a gloved finger for approx. 15–20 s. Then, wait 5–10 min to see if the reflex for defecation can be triggered. Can be repeated 2–3 times.

Recommendation 9: The use of rectal evacuation techniques must be carried out correctly according to the individual and the paralysis-specific situation, following professional instructions. Evacuation techniques designed to trigger reflex evacuation are only useful for the upper lesion type, whereas digital evacuation is useful for both lesion types.

Level of evidence: expert consensus (100%).

Physical measures

Apart from the sitting position for defecation, any form of movement can have a positive effect on stool transport. The following physical measures can be used in a targeted and supportive manner.

Pelvic floor exercises/biofeedback for incomplete SCI/D: The most important prerequisite for successful pelvic floor training is the ability to sense the pelvic floor and to be able to tense and relax it in a targeted way. Pelvic floor training is primarily carried out under guidance and can be supported by functional electrical stimulation or biofeedback if necessary [12].

Manual or apparatus abdominal massage: This serves to stimulate peristalsis, reduces colonic transit time and increases stool frequency [13].

Heat applications, e.g., in the form of wraps (possibly also moist heat), can relieve spasms and pain and support stool transport [14]. Etheral substances can support this. Caution - Risk of burns due to reduced sensitivity!

Drug therapy

Since neurogenic rectal dysfunction is often at the forefront of SCI/D, attention must first be paid to regular rectal emptying, which can be initiated with rectal laxatives. Depending on intestinal motility and stool consistency, oral laxatives can also be used (see Table 2).

Escalating of medications

Recommendation 10: Level 1 and 2 oral laxatives should be used to modulate stool and support bowel function. Level 3 oral laxatives should only be used for short periods in people with SCI/D and neurogenic bowel dysfunction (see Fig. 3).

Level of evidence: expert consensus (100%).

Surgical treatment measures

Botulinum toxin-A/External anal sphincter (EAS). In cases of anal sphincter spasticity associated with problems during evacuation, insertion of therapeutics or digital evacuation, particularly if these processes lead to the triggering of autonomic dysreflexia and measures such as stretching, reduction in sphincter tone can also be attempted by off-label therapy with botulinum toxin-A after conservative therapeutic measures have been exhausted. Experienced practitioners inject a few units (e.g., 10–40 IU of onabotulinum toxin) intramuscularly into the four quadrants of the external sphincter muscle under ultrasound or electromyography (EMG) guidance [15]. In tetraplegics at risk of autonomic dysreflexia, the injection should be given while monitoring blood pressure; incontinence after too high a dose should be avoided.

Recommendation 11: Botulinum toxin-A can be used for outlet constipation due to a spastic anal sphincter (off-label).

Level of evidence: expert consensus (100%).

Sacral neuromodulation/stimulation. After conservative therapeutic measures have been exhausted, sacral neuromodulation (SNM) can be considered for select patients with neurological incomplete SCI/D [16]. Predictors of therapeutic success are not certain; inter alia, the length of time between neurological diagnosis and SNM is discussed as a factor [17]. To evaluate the 3–4-week test phase, the influence on the quality of life should be examined in addition to clinical parameters.

Combined with other treatments (conservative bowel management), SNM can help improve multiple symptoms of neurogenic bowel dysfunction [18].

Recommendation 12: After conservative therapeutic measures have been exhausted, sacral neuromodulation (SNM) can be considered for select patients with neurological incomplete SCI/D.

Level of evidence: expert consensus (100%).

Malone stoma. This is a continental appendicostomy for antegrade irrigation of the colon. The literature reports good results in children with spina bifida [19].

Table 2. Rectal and oral laxatives.

A) Rectal laxatives	
Suppositories	<ul style="list-style-type: none"> · CO₂-releasing suppository, which must be moistened before insertion (no Vaseline!), releases approx. 80–100 ml of CO₂ gas, which causes the rectal wall to stretch and thus stimulates the receptors. Stimulation of the intestinal wall by the gas bubbles is another effect. This stimulates peristalsis. · Glycerine (highly concentrated) is hygroscopic and exerts a mild osmotic secretion stimulus on the mucosa of the rectum and simultaneously initiates the defecation mechanism. · Bisacodyl has a laxative effect by stimulating the peristalsis of the colon and the accumulation of water and electrolytes in its lumen. When applied as a suppository, the rectal wall tension is also increased, as occurs physiologically during defecation.
Enema	<ul style="list-style-type: none"> · Sodium dihydrogen phosphate causes an osmotic pressure gradient so that more fluid flows into the intestinal lumen. The resulting filling and increase in pressure in the rectum stimulate intestinal peristalsis in a physiological manner. · Sorbitol, sodium dioctyl sulphosuccinate, docusate sodium has a stool-softening effect. Sorbitol is an osmotic laxative. Docusate in an aqueous sorbitol solution facilitates the penetration of water and fats into the intestinal contents as well as the wetting of the intestinal wall. · Sodium citrate, dodecyl(sulphoacetate), sodium salt, sorbitol solution 70% releases abundant water that is compounded even in the hardened stool ball. This results in softening the ball, which can now be discharged more easily.
B) Oral laxatives	
Dietary fibres with bulking properties	Increase in stool volume due to intestinal fluid absorption results in reflex stimulation of intestinal peristalsis. As the effect only occurs after a few days, these agents are not suitable for immediate stool regulation, e.g., psyllium husks (depending on experience, start with a "level teaspoon", can be increased after approx. 8 days if required).
Osmotically active laxatives	<p>So-called "stool softeners" bind water in the colon, increase the stool volume and thereby stimulate the peristaltic reflex. Glauber's salts are <u>not used</u> in the long-term treatment of NBD.</p> <ul style="list-style-type: none"> · Lactulose: Use adapted to stool consistency, start with 7.5–15 ml syrup (5–10 g lactulose) 1-2x/d, decrease or increase dose according to effect; Acute constipation: single use of 60–100 ml. · Macrogol (polyethylene glycol): Use adapted to stool consistency, start with 1 sachet/d, increase or decrease dose according to effect; Acute constipation: one-time use of 5–6 sachets to 1–1.5 l over 3–4 h.
Anti-absorptive secretory substances	<ul style="list-style-type: none"> · Anthraquinones: E.g., of senna or senna leaves, take approx. 12 h. before defecation, short-term use - 3 drg. to stimulate defecation. · Sodium picosulphate: 10–20 drops, take approx. 10–12 h before defecation, short-term use to stimulate defecation. · Bisacodyl: 5–10 mg/1d, take approx. 10–12 h before defecation, short-term use to stimulate defecation. <p>Side effects: The strong stimulant laxatives in particular - but also all others - can lead to disturbances of the electrolyte balance due to enteral losses of sodium, potassium, calcium and water if not used properly. "Intestinal sodium loss may further cause renal potassium loss via secondary hyperaldosteronism. The potassium losses decrease intestinal motility and increase constipation, so that a tolerance [dose increase] to the laxative may develop?"</p>

Recommendation 13: A Malone stoma may be considered as an alternative form of treatment for constipation or to achieve secondary continence for faecal incontinence.

Level of evidence: expert consensus (100%).

Conus deafferentation, sacral deafferentation (SDAF) and sacral anterior root stimulation (SARS according to Brindley)

If relevant autonomic dysreflexia occurs during bowel management (e.g., during digital stimulation and evacuation), deafferentation is a therapeutic option that can be considered after conservative measures have been exhausted. In NBD, the use of suppositories, the need for digital evacuation or the application of clysters under SARS can be significantly reduced [20]. Bowel function can be improved using SARS, and patient satisfaction with this therapy is high [21].

Recommendation 14: Deafferentation should be a treatment option for refractory autonomic dysreflexia in the context of bowel management.

Level of evidence: expert consensus (100%).

Recommendation 15: If deafferentation is indicated, the use of sacral anterior root stimulation to improve bowel evacuation should be considered.

Level of evidence: expert consensus (100%).

Colostomy

In the long-term course, approximately 10% of people with spinal cord injury undergo an ostomy [22]. In these selected cases, a colostomy can result in a significant improvement in quality of life [23]. The decision to create a stoma should not be delayed too long in these critical cases [24].

As a definitive solution in these cases, the colon should be drained to conduct terminal colostomy [23]. A double colostomy is also suitable as a temporary solution, e.g., for decubitus and faecal incontinence (minor surgical intervention and easier relocation).

The position of the stoma should be marked preoperatively by the surgeon or stoma therapist, especially taking into account the sitting position in the wheelchair and the hand function, and test use of an adhesive bag in the planned position is recommended [24, 25].

Recommendation 16: A definitive colostomy should be considered if all conservative measures have failed and constipation or faecal incontinence is refractory. A terminal colostomy is then to be created.

Level of evidence: expert consensus (100%).

Level 1	Level 2	Level 3
Rectal laxatives		
CO ₂ laxatives	Suppository based on lubricants (Glycerol/Sorbitol) Enema based on osmotic agents	Stimulant suppository (Bisacodyl)
Oral laxatives		
Stool modulating----->		Evacuative----->
Dietary fibres with bulking properties	Osmotically active substances	Anti-absorptive, secretory substances
<ul style="list-style-type: none"> · Linseed · Psyllium husks · Chia seeds · Oat flakes · Guar bean 	<ul style="list-style-type: none"> · Lactulose - Sugar/sugar alcohols 	<ul style="list-style-type: none"> · Antraquinones: - Senna leaves
	<ul style="list-style-type: none"> · Macrogols - Polyethylen glycol 	<ul style="list-style-type: none"> · Diphenolic laxatives - Sodium picosulphate - Bisacodyl

Fig. 3 Drug therapy escalation.

Complications

Inadequate bowel management or inadequate implementation of the recommended measures can lead to serious complications, both primary and long-term [26–34]:

- Abdominal pain/discomfort
- Anal bleeding
- Anal fissures

- Autonomic dysreflexia (in spinal cord injury above T6)
- Pressure sores
- Restriction of respiratory function
- Faecal impaction/paradoxical diarrhoea
- Haemorrhoidal disease
- Urinary tract infections
- Megacolon/megarectum
- Flatulence

Prolapse (rectal, anal)
Spinal spasticity

Flatulence

In SCI/D, flatulence is a serious clinical symptom that, in addition to physical symptoms (leakage of intestinal gases, loss of appetite, feeling of fullness, malaise, restricted mobility, etc.), can trigger serious complications such as respiratory insufficiency and intestinal paralysis leading to ileus or autonomic dysreflexia. The following factors can be causative: increase in the absolute volume of the intestinal contents (e.g., due to constipation), decrease in the tone of the abdominal muscles, food incompatibility (e.g., pulses, cabbage, leeks, onions), food intolerance or malabsorption, and spastic anal sphincter. Aerophagy (swallowing air) requires causal differentiation. Natural or synthetic antifatulants (carminatives) can be used to manage flatulence in combination with colonic massage and/or a prone position. Natural products are essential oils such as aniseed, fennel, caraway, coriander, peppermint leaves, and chamomile flowers [35]. They have a spasmolytic effect on the smooth intestinal muscles and an anti-fermenting effect on intestinal contents. Synthetic products include dimethicone and simethicone [36].

Recommendation 17: To reduce flatulence, the primary goal is to eliminate constipation. In addition to colonic massage and antifatulants, anal stretching to remove the air in the rectum may be helpful.

Level of evidence: expert consensus (100%).

Autonomic dysreflexia

Autonomic dysreflexia (AD) is a potentially life-threatening syndrome that can occur with spinal cord injury above T6 (rarely also with deeper paralysis) [37]. The risk is significantly greater with neurologically complete forms of SCI/D (frequency: 91%, compared to 27% in neurologically incomplete SCI/D) and increases with increasing duration of paralysis [38]. A sudden increase in blood pressure (in the sense of a “hypertensive crisis”) with consecutive bradycardia can be particularly threatening. Autonomic dysreflexia can manifest itself as throbbing headaches, increased sweating, flushing and goosebumps. Causes of autonomic dysregulation triggered by the intestine are stretching of the bowel/rectum, manipulations such as digital evacuation and rectal insertion of suppositories or transanal irrigation [39]. Distention of the bowel is the second most common precipitating factor after distention of the urinary bladder [40]. Symptoms of AD occur less frequently and to a lesser degree with transanal irrigation than with digital evacuation [39]. The instillation of lubricant containing lidocaine can also prevent the occurrence of AD during digital evacuation [41].

Recommendation 18: If there is a known risk of AD, precipitating triggers should be avoided as much as possible during bowel management.

Level of evidence: expert consensus (100%).

Bleeding

Occasionally, patients report bleeding in connection with bowel evacuation. Bleeding is often caused by injuries to the rectal mucosa or the haemorrhoidal cushions caused by manipulation during evacuation or irrigation. Injuries can be avoided by using sufficient lubricant, gloves and a gentle approach.

Recommendation 19: In cases of repeated bleeding, other causes of bleeding, such as tumours or inflammatory bowel diseases, must be ruled out.

Level of evidence: expert consensus (100%).

Faecal impaction/paradoxical diarrhoea

A special situation exists with the so-called “faecal impaction”. Repeated incomplete bowel movements lead to a progressive

build-up of stool masses in the colon up to the development of a coprolite (faecal stone). These stool masses are processed again by the microbiome of the colon. This results in a fermentation process that leads to liquefaction of the stool in the aboral region and simultaneously increases the gas pressure above the stool column. Moreover, the coprolite triggers the recto-anal inhibitory reflex (RAIR), which relaxes the sphincter ani internus muscle. Either liquid or foul-smelling stools are excreted and/or there is an explosive discharge if sufficient pressure has built up. Without knowledge of the causes, this is mistakenly interpreted as banal diarrhoea and possibly treated with loperamide (slows down bowel movement), which eventually aggravates constipation. Detection of a coprolite is performed by digital palpation, sonography or radiology (empty abdominal radiograph). Occasionally, a contrast enema will confirm the diagnosis. CT is usually unnecessary (except to rule out a causative stenosing tumour).

DISCUSSION

The majority of persons with SCI/D, even those with very incomplete injuries, experience problems with defecation, such as constipation, difficulty with faecal evacuation and faecal incontinence. The consequences of neurogenic bowel dysfunction (as well as neurogenic bladder dysfunction) often have a greater impact on the quality of life of those affected than the restrictions on mobility.

It is therefore extremely important to provide the best possible support and recommendations for comprehensive care to the affected persons themselves and also to their caregivers from the various professions.

The scientific evidence for recommendations on the management of NBD remains low (SCIRE 2014 [42]). A recent Cochrane (2014 [43]) review has shown that the published research evidence on the treatment of NBD is sparse. Only 20 randomised trials of generally poor quality were identified and it was found that it is generally not possible to make recommendations based on this evidence. At the time of the development of this guideline, there were no guidelines worldwide with a higher level of evidence than expert recommendations. The multidisciplinary development group of the present guideline with experts from different disciplines felt the need to raise the evidence level of the recommendations and therefore developed concrete recommendations at consensus level in a structured process.

Only last year, two guidelines were published [44, 45] that describe a clear methodology for the evidence search and use the GRADE [46] approach for the recommendations. In terms of content, the recommendations of the two aforementioned guidelines correspond to the recommendations of the German guideline presented.

The expert group defines the goals of bowel management following SCI/D as follows:

- self-management leading to regular and predictable bowel emptying at a socially acceptable time and place
- using minimal physical and pharmacological interventions to achieve complete bowel emptying within an acceptable time frame
- the prevention of bowel accidents, constipation, autonomic dysreflexia (which can be life threatening) and other complications.

Guidelines can only be successful in so far as they are applied in everyday life. Of course, the selection and application of the measures described must always take into consideration the individual situation of the person concerned, and the correct application is always a prerequisite for success.

The lack of application of the GRADE methodology to assess the quality of the available evidence and the strength of the derived

recommendations is certainly a limitation of the present German guideline. According to the rules of the German Guideline Society, the validity of a guideline is limited to 5 years. Then an update of the content must be prepared. In this update, an improvement of the methodology of guideline development (e.g., evaluation of systematic reviews and meta-analyses according to the PRISMA statement, application of the GRADE approach for recommendations) is intended.

CONCLUSION

The guideline was developed by a multiprofessional interdisciplinary team at a consensus level with predominantly a small amount of evidence due to a lack of meaningful studies.

Individual bowel management must be developed on the basis of an adequate diagnosis and considering the different lesion types. Due to the multifactorial influenceability of the intestine and the individual neurological deficit, a simple to-do checklist is not effective.

Various and complex bowel management programmes are the basis of the treatment of neurogenic bowel dysfunction. Often, more than one procedure is required to develop an effective bowel routine. A balanced, fairly high-fibre diet and sufficient fluid intake are important components of bowel management. In addition, rectal emptying techniques and emptying aids as well as physical measures constitute the conservative part of bowel management. Rectal or oral laxatives are often used to support these conservative approaches. The use of these drugs is escalating.

Surgical interventions such as sacral neuromodulation, deafferentations with anterior root stimulation, Malone stoma and colostomy are the final therapeutic options if conservative treatment is not sufficiently effective.

In NBD, the overall aim of bowel management is to reduce bowel-related complications and to improve the quality of life of those affected.

Title of the long version guideline

Neurogene Darmfunktionsstörung bei Querschnittlähmung, Classification S2k, AWMF-Register-Nr.: 179-004, Published 31.08.2019, Valid until 30.08.2024.

DATA AVAILABILITY

The data described in the article are available from corresponding author on reasonable request.

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AUTHOR CONTRIBUTIONS

IK drafted the manuscript, VG and RB revises the manuscript. All authors read and approved the manuscript.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

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