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Concept for NMD Care Management

Project CARE-NMD-CH: Phase B

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1 Introduction

1.1 Initial situation of the Care-NMD-CH project

On behalf of the Swiss Muscle Society, the Zurich University of Applied Sciences (ZHAW) is conducting the Care-NMD-CH project in collaboration with the Cantonal Hospital St. Gallen, the University Children's Hospital Zurich, the University Hospital Zurich, the Inselspital Bern and the Swiss Foundation for Muscle Disease Research, as well as other cooperation partners.

The results of the ACTUAL analysis of the care situation (Phase A) can be read in the Phase A interim report. In phase B, the project aims to develop an evidence-based and family-centred concept for NMD care management based on the findings to date. The concept is to be implemented within the framework of a coordinated service by NMD care managers in neuromuscular centres (NMZ) and subsequently examined for its benefits for those affected and their family members, for the treatment team and for the health organisation (phase C).

1.2 Background

Neuromuscular disorders (NMDs) are rare genetic conditions that have serious implications for affected individuals and their families (Cohen & Biesecker, 2010; Magliano et al., 2015; Pangalila et al., 2012; Uttley et al., 2018; Waldboth et al., 2016). The care of NMDs is complex and requires a coordinated, interprofessional approach to care. (Birnkrant, Bushby, Bann, Alman, et al., 2018; Bushby et al., 2005, 2010). Currently, there is no primary causal therapy for the vast majority of NMDs. Affected individuals are affected by progressive muscle wasting, weakness, recurrent health crises and limited life expectancy (Amato & Russell, 2008; Brandsema & Darras, 2015; Falzarano et al., 2015). Due to improvements in symptomatic treatment and new technologies, affected individuals are surviving longer than ever before. Family caregivers are thus exposed to increasing care demands, high burden and increased risk of health problems for a longer period of time. (Waldboth, Patch, et al., 2021). The most difficult phases of the disease include diagnosis, loss of walking ability and major life transitions, such as the transition of an affected young person into adulthood and the late stage of the disease. Affected individuals and their families would benefit from the provision of evidence- and family-centred NMD care management. The following chapters define these terms and concepts.

1.2.1 Clarification of terms

1.2.1.1 Care Management

Care management, by definition, involves a wide range of services over an extended period of time. These services aim to optimise the quality of care for people living with complex conditions (Goodell et al., 2009). Coordinated activities can reduce costs if, for example, duplications are avoided and medical services are reduced. Through coordination on the part of care managers, affected persons, their relatives and professionals are enabled to deal more effectively with the medical and nursing requirements of the illnesses and the associated health and psychosocial problems, which increases the self-efficacy of ill persons. (Goodell et al., 2009; McCarthy et al., 2015). According to the literature, care management includes services in the following areas:

- personal contacts with affected families, e.g. during counselling sessions and, if necessary, during home visits;
- supporting those affected and their relatives in dealing with the disease and coping with crises;
- the education and training of affected persons and relatives;
- the involvement of professional and informal services involved in care; and
- coordination and communication in the care network.

Care managers are experts, in this concept experts in the care of people with NMD, and as part of their service they enable affected people and their relatives, other professionals and informal service providers to recognise early warning signs of deterioration and to act accordingly (Goodell et al, 2009; McCarthy et al. 2015). Care managers pool information and coordinate the people involved in the care network by monitoring the course of the disease, promoting information flow and collaboration, and thus enabling joint and anticipatory treatment. The view of the entire care network and the cooperation in the interprofessional treatment team are essential for the care of persons with NMD. (Andersen et al., 2012; Birnkrant, Bushby, Bann, Apkon, Blackwell, Brumbaugh, et al., 2018; Birnkrant, Bushby, Bann, Alman, et al., 2018; Birnkrant, Bushby, Bann, Apkon, Blackwell, Colvin, et al., 2018; Mercuri et al., 2018).

1.2.1.2 Family-centred care

Family-centred care involves a systemic approach that focuses not only on the person affected, but also on the whole family system. (Kaakinen et al., 2010; Wright et al., 2014). The terms family, family members and relatives are used as synonyms in this document and family is defined as "people who either live together or are in close contact with each other" (Gudmundsdottir & Chesla, 2006) and who are "either biologically, emotionally or legally connected" (McDaniel et al., 2005). The health of the family as a whole can be promoted by family-centred interventions on the part of care managers and thus positive effects can be achieved for those affected and their relatives. An illness not only affects the person with the illness, but also influences the lives of the family members. At the same time, the family as a social system has an influence on the state of health and the well-being of each individual family member and thus has an impact on the health of ill family members. (Rolland & Williams, 2005). Family members such as parents or partners are often the most important reference and support persons for the ill person and perform a large part of the care and support work. Family caregivers usually experience their task as enriching, but also as stressful. (Pangalila et al., 2012). Thus, a high burden on the relatives can in turn have a negative influence on the course of the disease of the ill person. A systemic approach to care makes sense because it takes into account how family members relate to each other, interact, influence each other and what family behaviour supports coping with the disease and with important life transitions. (Feetham & Thomson, 2006). According to the Federal Office of Public Health (FOPH), in addition to adults, children, adolescents and pensioners in Switzerland also care for their ill loved ones. Often, more than one family member provides care and support, whereby various tasks in the area of support can be in the foreground. On the one hand, relatives can take over administrative tasks, provide help in everyday life (e.g. with activities of daily living, in the household), give emotional and psychosocial support or assist with coordination. (Otto et al., 2019).

1.2.1.3 Evidence-based practice

Evidence-based practice shapes the service delivery of NMD care management. Evidence-based practice consists of 4 components: 1) the clinical experience of professionals, 2) evidence from research, 3) the values and expectations of individuals and families, and 4) the context and circumstances of the local context. (Rycroft-Malone et al., 2004). The clinical experience of professionals results from many years of practical work and life experience and is often intuitive. Professionals also often draw on the experiential knowledge of other professionals. (Rycroft-Malone et al., 2004). Evidence from research is only one element that contributes to decision-making. In addition, new knowledge is constantly being generated, which requires constant further training and a transfer of the latest findings into practice, adapted to the local context. The involvement of the person affected and the integration of the experiences and preferences of the person with the disease are central, as is the consideration of institutional structures and processes and local and national guidelines. The combination of these four components is necessary to make evidence-based decisions and derive interventions that enable effective care. Existing evidence from research should be reviewed before deriving interventions, as the application to decision-making in practice can always be individualised and not blanket for a group (Scott & McSherry, 2009).

1.3 Aims and research questions

Project phase B aims to develop a comprehensive evidence-based and family-centred concept for NMD care management. Based on the results of the interim report from phase A, this concept was developed taking into account current evidence and with the involvement of experts.

The short-term goals include the development of a comprehensive care management concept and the preparation for phase C: implementation and evaluation. The standards and optimised processes introduced by the concept should enable the professionals involved in the treatment process to work together in a coordinated manner and provide high-quality care for those affected and their families. Inter-cantonal cooperation is also to be promoted and simplified by establishing the concept and by consolidating and expanding a professional network.

In the medium term, the services of care management will become established and will thus be part of the standard of care for NMD patients in the NMZs participating in the project. Care management is actively involved in the care of newly diagnosed patients as well as in questions or crises of patients who have already been admitted. The focus is on maintaining the quality of life of those affected, promoting their self-efficacy as well as supporting the family and reducing the burden on caring relatives. The care services can be coordinated, the flow of information can be ensured and the documentation of the course of the disease can be standardised, which strengthens interprofessional cooperation and contains potential for cost reduction. Overall, in the long term, in addition to improving the quality of care for affected persons and families, the NMZs involved in the project aim to provide standardised, evidence-based and family-centred care for NMD affected persons and their families throughout Switzerland. To this end, information about the care management concept is provided throughout Switzerland and the documents developed are made available to all persons involved in care. Finally, results are presented nationally and internationally in publications.

The following research questions guided the development of this concept:

What comprehensive approach to NMD care management needs to be adopted as best practice for Swiss NMZs, including evidence-based and family-centred services?

a. What are the recommended competences of care managers?
b. What evidence-based and family-centred services are recommended for care managers?
c. How do care managers work efficiently with doctors and an interprofessional treatment team?

2 Method

This project uses a mixed method design (quantitative and qualitative methods) (Burns & Grove, 2009; Westhues et al., 2008). It is national in scope and involves several health facilities in the three Swiss language regions. It has been reviewed and approved by the competent ethics committee (BASEC No. 2020-01882) and will be conducted in compliance with Swiss legislation and the Data Protection Act. As mentioned in the introduction, the following three phases are distinguished within the project:

- Phase A: Analysis of the current supply situation
- Phase B: Concept development for NMD care management
- Phase C: Implementation and evaluation of NMD care management

Phase B was implemented in two work packages: 1) A literature review on evidence-based and family-centred interventions and the development of an outline of NMD care management using a logical model. (Silverman et al., 2007)2) The discussion and further development of the NMD Care Management concept with a group of experts (Task Force Myosuisse, Sounding Board, Care Management experts) according to a creative cyclical action research process consisting of repeated phases of reflection, planning, action, observation, reflection and re-planning. (Glasson et al., 2008).

3 The complex care of people with NMD

A wide range of professionals from different settings, as well as many informal services, are involved in the care of people with NMD in Switzerland (Waldboth, Hediger, et al., 2021). Families often assume the majority of the care and support tasks and are supported in everyday life by their social environment, by assistants and/or by professionals. Many affected persons and their families have regular contact with medical and nursing services in inpatient, outpatient and rehabilitation settings, as well as with therapists. The formation of an interprofessional treatment team is indispensable for the holistic care of people with NMD.

The Care-NMD-CH Phase A project identified a number of gaps in the care of people with NMD in Switzerland. (Waldboth, Hediger, et al., 2021). In order to better support people with NMD and their family members in the future and to coordinate the many professional and informal services involved in the best possible way, the activity profile of NMD care managers is outlined below.

NMD Care Managers, who are the focus of this concept, are based in the NMZs and mostly work on an outpatient basis. They are not intended to compete with existing services, but to provide complementary support to those affected and their families, depending on their needs and situation. This includes, for example, support during challenging phases of illness and life, the promotion of interprofessional cooperation and support for the coordination of care services. In order to have an overview of the living and care situation of those affected and to support them through targeted interventions, care managers need, in addition to specialist knowledge of NMD, a broad knowledge of the main areas of care, the needs of those affected and their families and knowledge of the services mentioned in Figure 1 and their offers. This is the only way that NMD care managers can refer patients and family members to other services as needed, e.g. to social workers for legal and insurance-related issues or to the psychological service for psychosocial stress. In the future, the use of NMD care management in NMZs can complement existing care services and optimise care, which has a positive effect on the quality of life of those affected, the burden on family members and interprofessional cooperation within the treatment team.

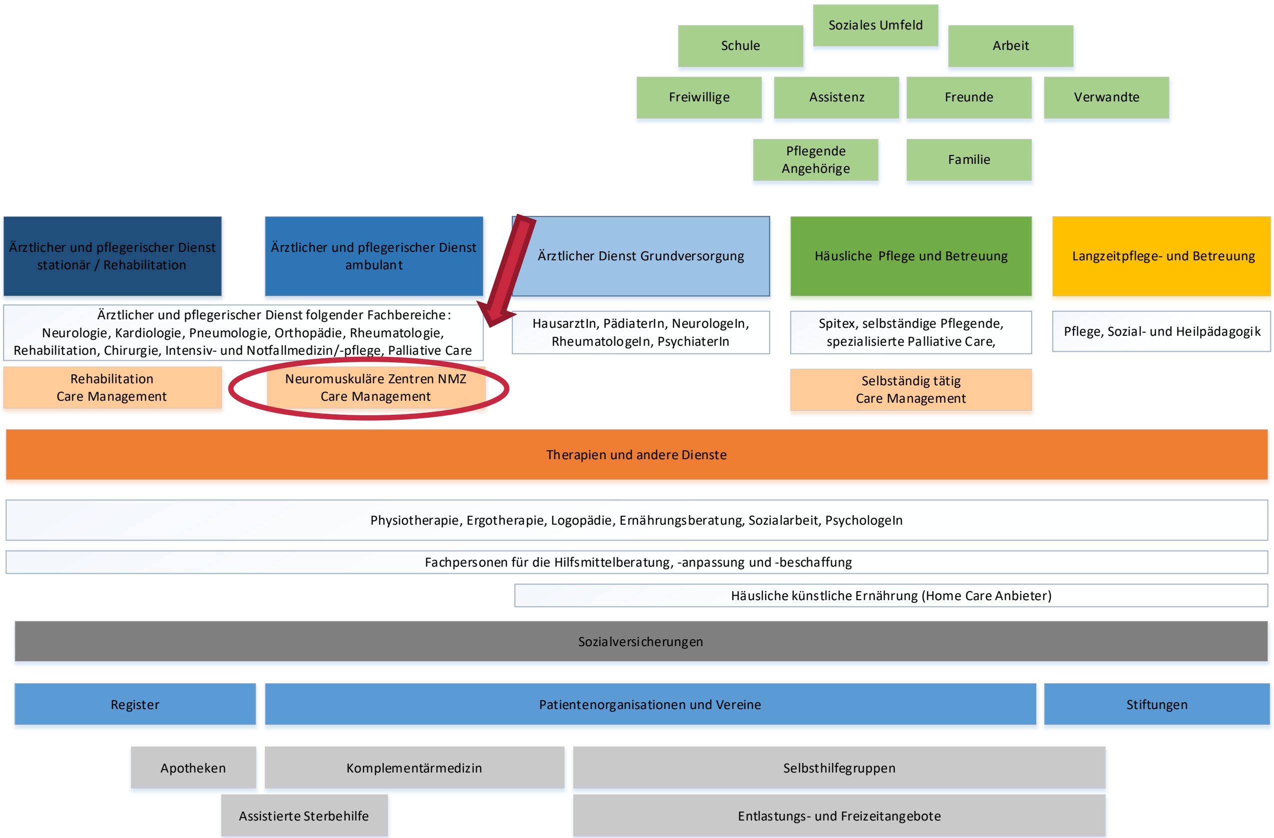


Figure 1: Care situation of people with NMD in Switzerland (adapted from Waldboth, Hediger, et al. 2021)

The interprofessional core team of the treatment team in the NMZ consists of the medical management (medical service neurology) and the NMD care managers. Depending on the symptoms of the patient, other specialist services (e.g. cardiology, pneumology, orthopaedics, rheumatology, rehabilitation, surgery, intensive and emergency medicine/nursing, palliative care) as well as therapists (e.g. physiotherapy, occupational therapy, speech therapy, nutritional counselling, social work, psychologists, specialists for counselling, adapting and procuring aids, home artificial nutrition (home care providers)) are involved. The core team of the treatment team in the NMD centres works closely with the persons affected and their families, with the specialists involved within the hospital and with external services (e.g. primary care providers, home care providers, patient organisations, social insurance companies). The NMD care managers play an important role in interface management and involve and inform the relevant persons and services as required.

4 The competences of NMD care managers

The following section describes the requirements and competence profile of NMD care managers. This job profile is formulated comprehensively and includes paediatric as well as adult care. Care managers with appropriate experience and education or training will be able to provide the majority of the services described, depending on the institutional framework. Whereas care managers who are novices may need to acquire the necessary competences or they may be implemented by different people through a team approach. The present concept will be evaluated within the framework of the Care-NMD-CH Phase C project and subsequently revised.

4.1 Requirements for NMD Care Management

Based on the analysis of the current care situation (phase A) and taking into account existing best practice evidence, the following formal, personal and organisational requirements for NMD care managers were formulated:

Formal requirements

- Completed basic training in healthcare at tertiary level (HF, FH or university), preferably in the field of nursing or in a related field, ideally nursing expert APN (Advanced Practice Nurse) at MSc level.
- Practical experience with NMD sufferers and their families or willingness to acquire this (e.g. experience in the specialties of neurology, intensive care, respiratory medicine, rehabilitation, palliative care).
- Practical experience in paediatrics for care managers caring for children and adolescents
- Advanced training or continuing education in the field of NMD or willingness to participate in such training or continuing education on an in-service basis. A compulsory basic course in NMD Care Management is offered within the framework of the project with the following integral components:
    - Knowledge in the field of medical and nursing care of NMD sufferers and their relatives (pathophysiology, therapy, nursing focus for common NMDs - ALS, SMA, DMD).
    - Knowledge in the field of care management / case management / coordination
    - Knowledge in the field of legal and financial frameworks, social insurances and aids
    - Knowledge in the area of regional care structures in specialised and primary care for NMD sufferers

Personal requirements

- Knowledge of own competences and their limits, knowledge of the members of the treatment team and reflective practice skills to recognise when to involve other professionals from the treatment team (e.g. social work, psychology).
- Family-centred basic attitude and systemic orientation of the services offered
- Services offered correspond to evidence-based practice (best practice according to current evidence, continuous further training in the sense of life-long learning).
- Basic ethical attitude and diversity competence in the care of NMD sufferers with differences
- Analytical skills and competences in networked thinking
- High social competence and communicative skills
- High competence for intraprofessional, interdisciplinary and interprofessional cooperation

Organisational requirements for care management were formulated by Brügger et al. (2019) and can be transferred to NMD care management:

- a counterpart who is accessible and has enough time for concerns
- Personal continuity, i.e. a contact person who is available for questions and discussions not only once but for a longer period of time, who knows the history of the disease/life and with whom there is a relationship of trust.
- A person who pro-actively approaches affected persons and relatives, asks questions and addresses issues that the affected persons and relatives themselves have not even thought of yet
- a neutral counsellor, i.e. the interests of an institution or organisation should not be represented, but the needs of the person concerned and the family should be in the foreground.

4.2 Acquisition of competences

Case Management Switzerland defined a requirements profile with 16 key competences divided into the following 4 basic competences according to KODEX. (Netzwerk Case Management Schweiz, 2016):

1) Social-communicative competence;
2) Personal competence;
3) Activity and action competence and
4) Subject and methodological competence.

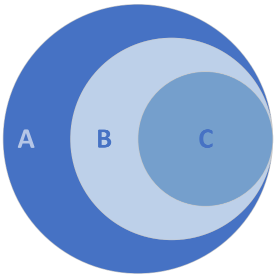
This requirement profile can serve the supervisors of care managers as a grid for formulating a context-specific requirement profile for NMD care management and professionals themselves as a self-assessment and self-evaluation tool. Care managers can reflect on their existing competences and systematically plan their competence development. Table 1 specifies the basic competences, which can be found at: https://www.netzwerk-cm.ch/sites/default/files/uploads/30.09.2016_infounterlage_kompetenzprofil_cm_finale_version_0.pdf

Basic skills	**Social-communicative competence**	**Personal competence**	**Activity and action competence**	**Technical and methodological competence**
Key competences	Communication skills	Credibility	Decision-making ability	Interdisciplinary skills
	Relationship management	Self-management	Results-oriented action	Analytical skills
	Willingness to understand	Holistic thinking		Judgement
	Conflict resolution skills			
	Dialogue skills, customer orientation			
	Problem-solving ability			
	Advisory capacity			

Table 1: Basic and key competences according to KODEX® (Netzwerk Case Management Schweiz, 2016)

5 Scope of activities and services of the NMD Care Managers

The listing of benefits (Figure 2) is done in:



Area A: Direct clinical practice: services for affected persons and their families

Area B: Interprofessional cooperation in the treatment team

Area C: Professional development and networking

Figure 2: Services of the Care Managers Areas A-C

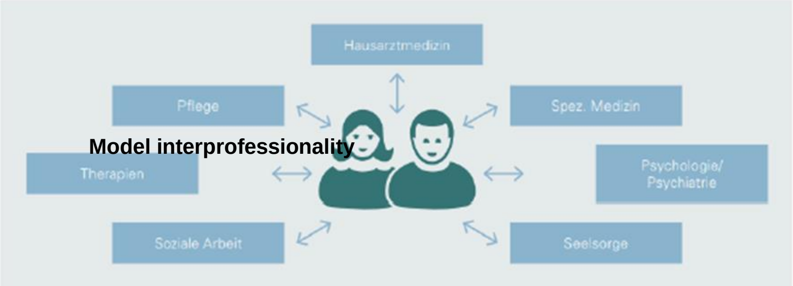
As elements of coordination and navigation are integral parts of areas A-C, these aspects are described in an introductory and superordinate manner.

5.1 Coordination and navigation

The care situation of people living with NMD is complex and multi-layered. Many professionals and informal services (Figure 1) are involved, each contributing to the health and well-being of the person and their family through their expertise (Waldboth, Hediger, et al. 2021). Patients and family members benefit when they are not the sole hub for coordination between these parties (hub model), but are included as active partners in the treatment team and receive support from the NMD care managers in coordinating and navigating through the care system (interprofessionality model) (Figure 3). Affected persons and relatives as partners are supported where they need support, it is important to avoid over- and underprovision and to promote the independence of the persons.

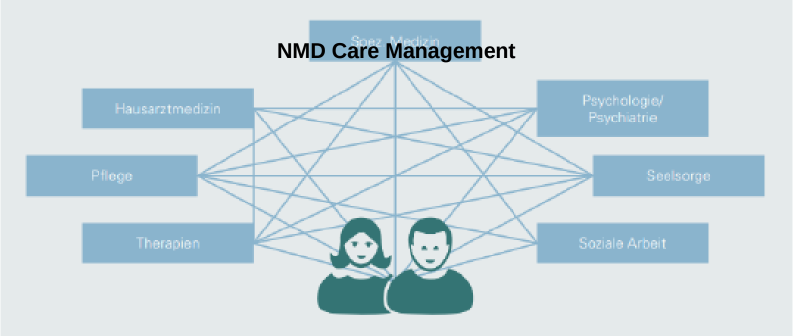
Model turntable

Model interprofessionality



Model interprofessionality

Figure 3: Model hub and interprofessionality adapted, according to Brügger et al. 2019 cited in (Wittwer, 2021)



NMD Care Management

Due to their competences, NMD care managers working in NMZs are predestined to have an overview of the care and treatment pathway and to take on such a coordinating-supporting role. On the one hand, they can have a positive effect on ensuring the flow of information and communication at the level of the treatment team, and on the other hand, they can support those affected and their families in navigating through the care system. Coordination means matching individual activities of a system with a specific goal (Schulte-Zurhausen, 2014). Coordinated care is understood as the totality of all processes that are needed to ensure the quality of care. The person concerned is the focus of interest throughout the entire period of care (Federal Office of Public Health [FOPH], 2019). In order for NMD care managers to be able to take on activities in the area of coordination and navigation, structural, temporal and financial resources must be available (e.g. resources for information collection, documentation and services in the area of ensuring the flow of information). In their own area of competence, care managers must be able to work independently and be well embedded in a functioning interprofessional team with established cooperation. Within the hospital as well as with external services, very good networking and cooperation is sought so that the NMD care management services can function in a complementary way and are not perceived as competition. In the following, the services in the areas A-C are described, which, depending on the competence of the care managers concerned, are fully implemented by this person or by means of a team approach.

5.2 Area A: Direct clinical practice - services for affected persons and families

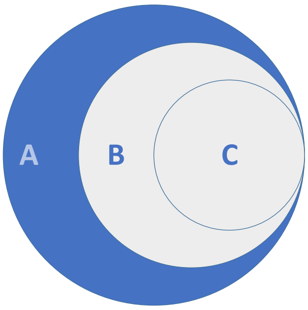


Figure 4: Services provided by care managers Area A: Direct clinical practice

In the area of direct clinical practice, it is useful to work according to established practice concepts. The SENS model from palliative care is a comprehensive tool that can be adapted to NMD care. SENS is the abbreviation for Symptom Management, Decision Making, Network / Emergency Planning and Support. It is a thematic structure for forward planning (Fliedner et al., 2019). The aim of SENS is to create a cross-institutional and quality-improving structure that enables professionals to identify resources, concerns and priorities of people affected. With the help of SENS, a multidimensional treatment plan can be developed that promotes self-efficacy in medically and nursing demanding situations. Specifically, SENS helps to find coordinated interventions to defined goals and to improve the flow of information between the treatment team, the affected persons and their relatives. In addition, SENS can serve as a training structure and support the financing of interventions. (Fliedner et al., 2019).

5.2.1 Care Management Anamnesis

In the context of direct clinical practice, care managers collect information and carry out assessments. When collecting information, all relevant data that contribute to the recording and assessment of the situation are systematically collected during an anamnesis and recorded in writing, e.g. in the clinic information system or in the patient dossier. This includes recording information on the life and health situation, resources, problems, goals and relevant biographical data. This collection of information also serves to build up relationships and is the basis for mutual trust between the specialist, the person affected and family members. (von Reibnitz et al., 2015). The initial anamnesis is detailed and takes place during the first contact. The timing of this history should be coordinated within the interprofessional treatment team. In the course of the disease and the professional contacts, shorter case histories are taken.
For the systematic collection of information, an instrument was developed within the project that care managers can use for the case history (Annex 1: Case history form for paediatrics; Annex 2: Case history form for adults). It contains the following elements:

Part 1: Personal details
Part 2: Social history
Part 3: Medical history
Part 4: Symptoms / activities of daily living
Part 5: Therapies and treatment team

Based on this information, areas of stress and resources are described. A person's personal resources, which are assessed during the case history, consist of individual characteristics and knowledge. Each person has different abilities and thought processes to deal with challenging situations. In addition to human resources, there are material and spatial resources. Material resources include, for example, goods, finances, information or equipment that are available. Premises and infrastructure belong to the spatial resources (Cropley D. H. & Cropley A. J., 2018).
Goals are discussed together with the persons affected and their relatives. (Eychmueller et al., 2020). A care plan is then drawn up, measures are recorded and the interprofessional treatment team with the relevant specialists and contact persons is documented.

Anamnesis is a systematic questioning of the person in care. In addition to the anamnesis, further assessments can be carried out, e.g. physical examinations and other assessments. An assessment is derived from the English term "to assess" and means "to judge, to measure". An assessment serves to ascertain the situation of a person and his or her family as accurately as possible. For such an assessment, a variety of scales, tests, measuring instruments or documentation are available, depending on the information to be determined. The data obtained with the help of an assessment serve as a basis for evidence-based, structured treatment planning (von Reibnitz, Schümmelfeder, Hampel-Kalthoff, et al., 2015). Additional questionnaires or assessment instruments can be used for data collection and situation assessment (e.g. pain assessment). However, as the use of these instruments varies with respect to the respective disease, disease phase or institution, they are not listed here.

5.2.2 Promote symptom and self-management

On the basis of the assessment, care managers can initiate measures to promote symptom and self-management of those affected and their relatives. Symptoms, experienced changes in the biological, social or psychological functioning of the body, are experienced subjectively by each individual (Smith & Liehr, 2014). Symptom management is based on the theory that individuals can manage their symptoms in interaction with the environment. Health and illness influence the symptom experience and symptom management. Symptom management involves strategies aimed at eliminating, reducing or delaying symptoms. The development of effective management strategies for a symptom includes, for example, consideration of who, how, what, where and when action can be taken. (Smith & Liehr, 2014).

According to the symptom management of the SENS model von Fliedner et al. (2019) the clarification of the following questions by care managers in cooperation with those affected and their family members can be helpful:

- Which distressing symptoms are in the foreground or can be expected?
- Through what measures are they addressed?

Self-management involves patient education and the deliberate and structured use of aids, tools and behaviours to help people organise and develop themselves. The aim is to reduce stress and improve performance. Good management of time resources is one of the keys to successful self-management. (Bischof et al., 2019). Providing information, training, counselling and guidance are all aspects of systematic patient education. With the help of targeted and structured patient education, existing resources can be activated, deficits compensated for and self-management skills improved. Involving the relatives is important in this context (von Reibnitz, Schümmelfeder, & Hampel-Kalthoff, 2015; von Reibnitz, Schümmelfeder, Hampel-Kalthoff, et al., 2015).

5.2.3 Forward planning

People living with NMD and their families benefit from a forward-looking approach by the treatment team, with a focus on upcoming changes and on support during transitions and crises. This includes, for example, preparing for and supporting the transition from paediatric to adult care (Waldboth, Patch, et al. 2021). Likewise, preparing and supporting affected families during crises and end-of-life, including grief counselling. For many families living with NMD, conversations about the future are stressful; sharing experiences and testimonials from other affected families about dealing with change and challenging transitions can be helpful. Care managers can provide these contacts.

Development and transition

The transition to adulthood is accompanied by physical, cognitive and psychosocial upheavals (Bill & Knight, 2007; Santrock, 2013). Young people grow and develop sexual characteristics, become more detached from the family and become more self-reliant and independent. (McGoldrick et al., 2013). In addition to the developments associated with the life stage, NMD sufferers are confronted with a chronic, progressive or even life-threatening disease. Young people and their relatives, who have to deal with experiences of loss and their own finiteness during this time, need accompaniment and benefit from psychological support (Waldboth, Patch, et al. 2021). Here, care management can involve the psychological service if necessary.

This phase also includes the transition from paediatric to adult care. Young people with the disease and their family members must be adequately accompanied during this transition, and the transfer from paediatric to adult medical care should be structured and well prepared (Waldboth et al. 2016, Waldboth, Patch, et al. 2021). Thus, affected persons and their relatives are prepared for what to expect in the course of the disease and what kind of support they are entitled to. Paediatric care is very family-oriented, the relationship between affected persons, relatives and professionals has usually existed for a long time and they know each other well. The change to adult medical care requires a change of contact persons and also a change to adult care, which presupposes more independence and the assumption of decision-making power by the young persons concerned. In order to accompany affected persons and their family members during this transition, it is necessary that care managers inform them about possible challenges of this phase of life, ask for and understand the needs and experiences of the families, and plan further health care together with the families and the treatment team by prioritising the autonomy and independence of the affected young persons (Waldboth, Patch, et al., 2021). It is beneficial if the transition is prepared, the affected person is accompanied and the collaboration between paediatric and adult service providers takes place in joint sessions with the affected person and their relatives within a transition programme (e.g. "Ready Steady Go" transition programme). NMD care management can take a leading role here and the two care managers within the NMZ (paediatric as well as adult NMZ) should work closely together within the transition.

Crises and end of life

According to the Advanced Care Planning (ACP) concept, those who are seriously ill should be given the opportunity to have their values and wishes incorporated into treatment planning (palliative zh+sh, O. J.). According to the decision-making of the SENS model by Fliedner et al. (2019) the clarification of the following questions can be helpful for care managers:

- What are the wishes of those affected and their relatives?
- What are the treatment goals (change)?
- Is a care plan drawn up?
- What are wishes for the end-of-life phase?

Care managers address the creation of an advance directive and a treatment/emergency plan with the person concerned and their relatives as part of forward planning. An early clarification and written record of end-of-life measures (e.g. intensive care and re-hospitalisation) should be made so that this information is available to the interprofessional team at all times. In addition to the treatment team, which can now follow "guardrails", this advance directive is also known to the relatives (palliative zh+sh, o. J.). They can thus represent the presumed will of the person concerned if he or she becomes incapable of judgement. In emergency situations, affected persons and their relatives should be accompanied and cared for by the NMZ. (Birnkrant, Bushby, Bann, Apkon, Blackwell, Colvin, et al., 2018; Finkel et al., 2018). In general, interventional or palliative decisions must be weighed up. This should be done in consultation with the persons concerned and their families as well as the interprofessional treatment team. It is therefore necessary to develop a forward-looking treatment concept/palliative concept which can be adapted to the individual situation in each case. (Andersen et al., 2012; Finkel et al., 2018). If necessary, the core team will involve other specialists, e.g. palliative physicians, palliative nurses and/or the psychological service.

Working tools from the field of palliative care can be obtained from https://www.pallnetz.ch/arbeitsinstrumente.htm.

Grief counselling should also be included in the service catalogue as part of the forward planning of care managers. Many affected persons and relatives grieve because of the uncertainty of the future, but also for the common future, for the deceased ill person and for the loss of a loved one or the previous relationship. (Brügger et al., 2016). If necessary, specialists such as pastoral counsellors and the psychological service can be involved.

5.2.4 Educate and inform

Clarification is understood to mean the explanation of previously unknown contexts, e.g. in relation to a disease and therapy. Clarification can take place with the aim of simply passing on information

(Dudenredaktion, 2021a). The transfer of information basically includes the exchange of data; a circular exchange of information is preferable to a linear one. In a conversation, care managers can give information, e.g. explain the disease or the treatment, as well as accept it. Patients and relatives are seen as experts for their own health situation. Giving information serves to prepare affected persons and their relatives for expected transitions, possibilities or courses of events. (Wright et al., 2021).

Depending on the life and health situation, care managers can provide information on various topics:
- Diagnosis and clinical picture: symptoms, complications, warning signs
- Therapies and medicines
- Focal points in nursing and care
- Aids and devices
- Transitions and changes
- Crises and end of life (e.g. living will)
- Measures during pandemic (e.g. hygiene measures)
- Finances and insurance benefits
- Professionals, support and respite services, patient organisations and associations

The challenge for professionals is, on the one hand, to inform, involve and allow affected persons and relatives to participate in the decision-making process, and on the other hand, to make a certain selection and standardisation of information so as not to overwhelm them. (Brügger et al. 2019). If necessary, the care managers involve other professionals who have in-depth knowledge.

5.2.5 Guide and instruct

In guidance, knowledge and skills are imparted in a targeted and planned manner. Guidance consists of the three elements of information, training and counselling. (Quernheim, 2009). Whereas instruction is understood as step-by-step, oral and practical guidance with the aim of being able to carry out activities. (Dudenredaktion, 2021b).

The teach-back method is a teaching method used to ensure that the person concerned or their family members have understood the information. The patient or family member is asked to explain in his/her own words what he/she needs to know or do. It is important to emphasise that this is not a test or quiz. Rather, Teach-Back is a method to check whether sufficient knowledge or skills are available and, if necessary, to fill in gaps. The aim of this teaching method is to improve health literacy, adherence, patient safety and quality of care. (Institute for Healthcare Advancement [IHA], 2021).

Depending on the life and health situation, care managers provide guidance/instructions on the following topics:
- Administering medicines and therapies
- Nursing and therapeutic activities
- Handling aids and equipment
- Activities of daily living (nutrition, elimination, mobilisation, etc.)

Other professionals who are experts in specific topics are involved by the care managers at an early stage, e.g. physiotherapy in the instruction of the Cough Assist devices.

5.2.6 Counselling and office hours

In contrast to guidance, counselling, which can take place during the care manager's office hours and other contacts, is open-ended. This means that the decision as to which intervention is selected is made by the person concerned him/herself. (Quernheim, 2009). A consultation hour is a planned time frame that is available for a conversation. In the medical context, consultation hours are also often used to carry out consultations or treatments. (Dudenredaktion, 2021c). A consultation is understood to be a consultation or examination by a health professional (Dudenredaktion, 2021d). Preferably, NMD care managers can offer regular consultations of 30-90 minutes, depending on need (e.g. complexity, initial contact or course, phase of illness) and on the possibilities of the institution concerned (e.g. consultation on a consultation day, e.g. following the medical consultation). An interprofessional report and the written documentation of the results are important to ensure the flow of information with the treatment team, first and foremost with the medical service.

The aim of counselling is to prepare people to solve problems in a way that meets their needs. Planned counselling usually consists of four phases (Quernheim, 2009):

- The first phase is called the orientation phase, in which the situation of the person to be counseled is recorded.
- In the second phase, the clarification phase, all possible perspectives are presented.
- The change phase serves to generate efficient solution options.
- In the final phase, transferable strategies for action are defined.

Counselling is characterised by a process of interaction between one or more counselling seekers (e.g. affected persons with NMD and/or family members) and the counsellor. Systemic counselling is based on systems theory, which means that a person is not only seen as a detached individual, but rather as part of a whole system (e.g. a family system). A person's social system or environment is also affected by a disease. In systemic counselling, perspectives, views, problems and feelings of the whole system are uncovered and included. This systemic approach to counselling, which is essential for NMD Care Management, enables the view to be opened up and can lead to a change of perspective. (Barthelmess, 2014).

Depending on the needs, life and health situation, care managers advise on the topics mentioned below. It is important that care managers have a broad basic knowledge in many areas. They reflect on their own practice and know their limits. They advise those affected and their relatives within the framework of their own area of competence and involve other professionals from the interprofessional team who have higher expertise at an early stage. It is important to avoid duplication and competition at all times and to prevent under- and overprovision.

Topics:

- Diagnosis and clinical picture: symptoms, complications, warning signs
    - Explaining the pathophysiology for affected people and families
    - Explaining examinations and tests
    - Accompaniment before and after genetic examinations / consultations
    - Accompaniment during and after diagnostic interviews
    - Clarifying ambiguities / misunderstandings during or after medical consultations

➦ **Inclusion of medical service, psychological service, physiotherapy**

- Therapies and medicines
    - Best Practice / Guidelines
    - Alternative unconventional treatment methods
- Hygiene/measures during a pandemic

➦ **Inclusion of medical service, nursing services**

- Focal points in nursing and care
    - Mobility, transfer, positioning, decubitus prophylaxis, risk of falls
    - Excretion, bowel management, indwelling catheter, urinary condom
    - Nutrition, aspiration prophylaxis/swallowing training, nutrition via PEG, salivation
    - Breathing, ventilation, exhalation equipment, pneumonia prophylaxis
    - Communication and electronic communication
    - Burden and relief (offers for care, support and assistance in everyday life)
        - Professional care (e.g. Spitex)

        - Personal assistance (assistance budget)
        - Support and respite services
        - Patient organisations and associations

➔ **Inclusion of medical services, nursing services, physiotherapy, occupational therapy, nutritional counselling, speech therapy, counselling on aids, social services, patient organisations**

- Aids and devices
    - Wheelchair/wheel walker
    - Patient lifter
    - Structural measures
    - Applications (e.g. for social insurance)

➔ **Inclusion of physiotherapy, occupational therapy, aid counselling, social services, patient organisations**

- Diagnosis
- Transitions and changes
    - Development, transition to adult care
- Crises and end of life (living will)
- Social
    - Siblings
    - Friendships and acquaintances
    - Sexuality and partnership
    - Topics around childcare, school and work
    - Leisure activities

➔ **Inclusion of medical service, nursing services, palliative care, psychological service, child care, school, employers**

It is essential that care managers document consultations and the content of consultations, e.g. in the clinic information system or patient dossier, and inform the interprofessional team about them, e.g. by means of a short summary in a report with the medical service.

5.2.7 Outreach services and home visits

Depending on the context, needs and possibilities, care managers can carry out outreach services and home visits. This enables them to assess the family and housing situation on site, to identify resources and risks, and to build and strengthen a professional relationship with the persons concerned and their relatives. If outreach services cannot be provided, care managers can obtain important information through exchanges with professionals who go on site. The use of digital solutions (telemedicine) is also conceivable in order to gain insights into the home environment on the one hand, and on the other hand, to save the person affected from having to travel to an outpatient centre.

5.2.8 Organisation and networking

Care managers overview the care situation, organise services and network parties with each other. Under the terms organising or organising can be summarised all activities associated with the planning, implementation and enforcement of an intervention. (Schulte-Zurhausen, 2014). If activities are segmented during the organisation of work processes, there is a need to reassemble the elements formed in the process into the overall goal with the help of coordination. (Schulte-Zurhausen, 2014). Tasks of organisation, networking and coordination are within the scope of care managers. Whereas the coordination of appointments and organisation of consultation hours (administrative activities) are not the responsibility of care management and should be taken over by the secretariat.

According to the network/emergency planning of the SENS model by Fliedner et al. (2019), the following questions can be helpful for care managers to get an overview of the care situation:

- What is the family's housing situation
- Which experts are involved? Who has the lead?
- What support/resources exist in the family network?
- Emergency planning for complications/deterioration/emergency contacts?

Depending on the life and health situation, care managers support the organisation and networking with other services, e.g. by referring people to other services regarding the following topics:

- Organisation of aids
- Prepare applications for the financing of aids (e.g. suction device with the Lung League).
- Establish contact with
    - Social workers
    - Social security
    - Patient organisations
    - Professionals / regional services

5.2.9 Support for relatives

Relatives often take on a large share of the care and support of the person affected in everyday life (Waldboth, Patch, et al. 2021). They describe their supportive activities as enriching and at the same time they experience challenges and are burdened (Pangalila et al., 2012). For this reason, the inclusion of the family and the assessment of the needs of the relatives as well as targeted support for relatives on the part of care management is important. Care managers work in a family-centred way and assess the social situation of the family concerned (see chapter 5.2.1). According to the SENS model by Fliedner et al. (2019), the following further clarifications and information can be important for care managers:

- Family history, geno-, eco-, relationship chart
- Resilience of the relatives
- Support options/financial situation
- Grief counselling

Family discussions

The family interview is a key element in the care of people with NMD and their families. The 15-minute family interview described by Wright et al. (2021) includes the phases of relationship building, assessment with problem identification, attempts at solutions and interventions, and conclusion. Despite scarce time resources in the daily life of NMD care managers, the 15-minute family interview can be effective, informative and targeted. (Wright et al., 2021).
The interview should include the following key elements and be structured as follows:

- Beginning and ending with appropriate etiquette, such as introducing the full name and function of all participants in the conversation and explaining the purpose of the conversation.
- Identify family structures, relationships and resources (e.g. with the help of the geno-, eco-, relationship diagram).
- Three key questions / Asking family-centred questions
- Valuing and recognising the strengths of family members
- Evaluation of the benefit of the conversation and conclusion

The key or family-centred questions (Table 2) are an indispensable part of the family interview, as this is a way to involve family members in health care.

Questions	Purpose
How can we best help you and your family (or friends)?	Targets expectations and promotes cooperation
What has helped you most and least in previous situations?	Targets past strengths, problems to be avoided and repeatable successes
What is the biggest challenge for your family in relation to the situation?	Targets current or potential difficulties, roles and beliefs
Which family members or friends are we allowed to share information with? Which not?	Targets alliances, resources and potentially problematic relationships
What do you need to prepare yourself and your family optimally for the further course?	Aims at early planning
Who in your family do you think suffers most from the situation?	Targets which family member needs support and interventions most urgently
Is there a question you would like to have answered immediately in this conversation? Perhaps I can help you not answer this question immediately, but I will do my best to find an answer for you.	Targets one of the most pressing concerns or problems
What could I help you with most in this family conversation? What can be improved?	This shows your willingness to be supported by family to learn and work in partnership with them

Table 2: Therapeutic questions based on (Wright et al., 2021)

During the family interview, interventions are developed that promote, improve or maintain family functioning in cognitive, affective or behavioural domains. A change in one of these areas, may also have a positive impact on the other areas (Wright et al., 2021). Interventions can be offered on a partnership basis to achieve specific changes.

Perception, persuasion and information processing

Interventions from the cognitive domain often offer new ideas, opinions, beliefs about a particular health problem (Wright et al., 2021):

Valuing the strengths of the family and family members and changing their perceptions

Families who are chronically stressed tend to feel depressed and hopeless and see no way to overcome their problems. First and foremost, it is necessary to change the perception of the families, whereby an important approach is to recognise and value the perceived strengths of the individual family members. Focusing on the family's strengths provides a different self-image and thus a context for change can be created. The family is thus empowered to find their own solutions to their problems.

Information, instructions and other perspectives

In cases of serious illness, families have a great need for information and opinions from professionals. The situation, treatment plans and general information should be communicated in an understandable way, this also offers a different perspective. In this way, the family is also empowered to inform themselves and to obtain resources. (Wright et al., 2021). These measures improve knowledge and skills in dealing with the disease. (Chesla, 2010).

Division of tasks and communication

In the behavioural domain, the aim is to positively influence the interaction between family members. The motivation to change behaviour can be done by assigning certain tasks (Wright et al., 2021).

Encourage the care of relatives

Often family members are willing to participate in the care of their relatives if they feel supported by professionals and are encouraged to do so. However, it should be noted that this can lead to overburdening, which must be avoided.

Encourage rest breaks

Family members who are intensively involved in care and support often allow themselves too few breaks, which they would need. It must be possible for those affected to do without their usual care from time to time and to accept help from elsewhere, so that the care, coping and maintenance of their own health are balanced for the relatives. The care managers must take into account factors such as the severity of the illness, the availability of family members and financial resources. (Wright et al., 2021).

Develop rituals

Studies show that habits and rituals play a big role for families and strengthen their health. Chronic illness and psychosocial problems often lead to interruptions in rituals. Families should be encouraged to introduce new possible habits or therapeutic rituals. This leads to a strengthening of family bonds (Wright et al., 2021).

Effects of the disease on relationship quality and family behaviour

Interventions to promote family communication, communication in general and constructive conflict management help to promote family relationships. (Wright et al., 2021). Relationship-building interventions by care managers with a psychoeducational approach reduce the burden of care on families (Chesla 2010; Mahrer-Imhof & Bruylands 2014).

5.2.10 Psychosocial support and dealing with emotions

Brügger et al. (2016) show that the psychosocial burdens are weighted higher than the physical burdens of care, which makes optimal psychosocial support for families indispensable. Psychosocial support for affected persons and relatives includes having "an open ear" for their concerns (Brügger et al. 2016) and involving other professionals if necessary (e.g. psychological services).

Reduction or activation of intense emotions to stimulate problem-solving ability

Intense emotions can block the problem-solving capacity of families, so it is necessary to reduce or activate these emotions, thereby changing the affective domain of family functioning. This can be done by validating or acknowledging these emotions. Families with drastic diagnoses have the feeling of losing control and are afraid of (Wright et al., 2021). These strong emotions should be acknowledged so that the family can be reassured and have new hopes.

Encourage family members to tell the story of their illness.

In the interview, families should be asked to tell not only the story of the disease but also their life story, as in this way not only the suffering and the disease are addressed, but also the strengths of the family. This creates a trusting atmosphere for an honest exchange and is especially important in complex family constellations, so that all family members can describe their point of view. (Wright et al., 2021).

Mobilise support from the family

A trusting framework is important so that family members are encouraged to listen to and support each other's problems and feelings, which in turn mobilises the family's strengths and resources. (Wright et al., 2021).

5.2.11 Care for children, young people and adults

Characteristics of paediatric care

Paediatric Nursing Switzerland (2020) defines paediatric nursing as needs-oriented and patient-centred care, which includes the care of newborns up to the age of 18. In the following, the word children is used, but all stages from newborns to adolescents are meant. Care for children with acute, chronic and life-limiting illnesses of all ages that promotes movement and development, as well as cooperation in partnership with the whole family, form the basis here.

The core tasks in the general paediatric area are as follows:
- Protect the rights and health of children
- Responding to child-specific needs
- Train and support families and caregivers in caring for sick children with impairments (Pädiatrische Pflege Schweiz, 2020)

Specific issues for paediatric NMD care management are as follows:
- Focus on development
- Promotion of independence
- Focus on the family system, consideration of the wishes of those affected and their relatives
- Relief for the family, e.g. through early involvement of informal and professional respite services: Experience has shown that it is difficult to involve external support in paediatric care. It is particularly difficult for parents to accept external help and support for the care of their children. In the course of the illness, it happens that parents want to hand over part or all of the care to external services, e.g. due to high stress. At this later stage, it is often the young affected persons who no longer want to accept external care. External support in care and support - for example a Spitex, should be involved at an early stage, whereby it is sometimes challenging to find qualified personnel.
- Social insurances (e.g. birth defects)
- Childcare, education and the world of work (e.g. support in finding apprenticeships)
- Family planning
- Repeated, attentive communication and information on the disease adapted to the developmental stages of the children / adolescents, development of an understanding of the disease
- Transition from paediatric to adult care (see chapter 5.2.3)

Characteristics of adult care

The characteristics of adult care are so comprehensive and diverse that they are not addressed in the specifics. Therefore, the focus is on general care, which includes people of all ages and within all stages of life.

Specific issues for NMD care management in adults are as follows:
- Promotion of independence / decision-making ability
- Participation in social life and barriers in society
- Financing and social insurance: specifics in old age (e.g. aids, employment and IV)
- Work situation: For many people, work is an important activity that helps them to feel socially connected or fulfilled and to do work that is meaningful and enjoyable. (Minis et al., 2014). Sometimes work is also experienced as a burden, especially if the symptoms increase. It is often a challenge to find a suitable job with interesting activities that are within a framework that is feasible for the person concerned and compatible with the benefits provided by the insurer.
- Housing and care situation: There are hardly any adapted housing and care options for adults, which makes independent living and independence from the family almost impossible. Therefore, social isolation is sometimes very high. For ventilated persons, it is usually very difficult to find a place of care.
- Assistance: It is a challenge to find qualified personnel as personal assistance, as relatives and persons with a medical / nursing background cannot be financed through the assistance budget. By becoming an employer with assistance staff, the persons concerned have the corresponding responsibility of an employer.
- Childcare (if own minor children are present).

5.3 Area B: Interprofessional cooperation in the treatment team

5.3.1 Principles for cooperation

The Schweizerische Akademie der Medizinischen Wissenschaften [SAMW] (2020) defines principles of interprofessional cooperation in the health care system in Switzerland in a published basic document. These principles do not constitute guidelines, but serve as orientation with the aim of achieving coordinated communication and appropriate perception between the professional groups:

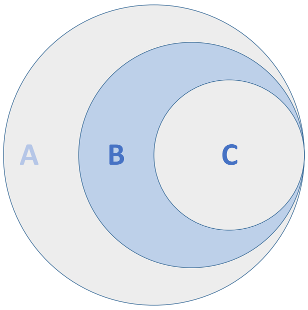


Figure 5: Services of the care managers Area B: Interprofessional cooperation

1. Involve affected persons and relatives in interprofessional cooperation in a spirit of partnership
2. Focus on the benefits of interprofessional cooperation
3. Living shared interprofessional decision-making
4. Taking responsibility for one's own work
5. Adapt interprofessional cooperation to the treatment setting
6. Promote culture of interprofessional cooperation through professional and specialist associations
7. Increase interprofessional competences through cooperative education, training and continuing education
8. Open communication, respect, trust as the cornerstone for integrated treatment and thus also for interprofessional cooperation
9. Leaders taking responsibility for cultural change
10. Advocacy for legal frameworks and funding opportunities to promote interprofessionalism

(SAMW, 2020)

Shared decision making is not just about informing the family about decisions or maintaining good communication about the procedure. Rather, it is about empowering the family to make decisions for themselves. Children are also involved in decision-making processes according to their age. In discussion situations, the preferences of the person and the family are identified and evidence-based treatment options are presented by the health worker. In shared decision making, both the person affected and the treatment team are experts. There is a kind of partnership that allows risks and opportunities to be identified together and the best possible options to be chosen. Several discussions may be necessary before a decision is made. (Makoul & Clayman, 2006). Figure 5 shows the services in the field of interprofessional cooperation, which will be discussed in the following.

5.3.2 Accompaniment during therapies, assessments and extended diagnostics

If indicated, care managers accompany patients during assessments and extended diagnostics (e.g. ECG/ECHO, LuFu or polysomnography, spinal X-ray) as well as during the planning and implementation of therapies together with other specialists (e.g. with the medical service, various drug therapies and associated assessments).

5.3.3 Organisation and networking within the treatment team

NMD care managers promote the establishment and maintenance of a care network. A care network serves to support affected persons and families in their everyday lives. It is composed of an interdisciplinary team, usually consisting of nurses, doctors and relatives. The establishment and maintenance of such a care network is usually challenging, as it consists of many different disciplines. Obstacles are insufficient exchange of information and undefined processes or tasks. Forming and maintaining a care network has a positive influence on the quality of care for those affected. (Imhof et al., 2016).

Interface management is one of the core tasks of care management (von Reibnitz, Schümmelfeder, & Hampel-Kalthoff, 2015). Interfaces are areas in care where overlaps occur. A possible interface can be, for example, the transition from inpatient to outpatient care. How well these interfaces are coordinated is a key success factor (von Reibnitz, Schümmelfeder, & Hampel-Kalthoff, 2015).
Interface management serves to reduce sources of error. It attempts to reduce a sharp separation between, for example, inpatient and outpatient care systems. Interface management is intended to ensure continuity within nursing and medical care.

5.3.4 Case discussions , roundtable discussions and reports

Interprofessional case discussions and reports are cross-workplace discussions and conversations about a specific treatment case. They serve to increase communication skills and exchange among health professionals. The interdisciplinarity helps to take different perspectives and can support in the perception of ethical dilemmas. In interprofessional case discussions, medical-ethical questions related to treatment and care can be discussed and clarified with a focus on maintaining and promoting the quality of life of the persons concerned and their relatives. (Hirakawa et al., 2020).
Roundtable discussions are planning discussions between the person affected, their relatives and the professionals. These discussions often deal with the further course of action or coordination around the disease and symptoms. (Eychmueller et al., 2020).

5.3.5 Contact person for professionals

NMD care managers are contact persons for other professionals. When a professional provides counselling on request for a short period of time and for a specific purpose, this is called a council. In a consultative consultation, professionals assist a family, for example, in making decisions and choosing a treatment. This ensures individualised, family-centred care (Kaakinen et al., 2010).

The care managers provide training for the interprofessional team and support them in challenging situations. Training, also called eduction, is understood as the targeted transfer or acquisition of information with the aim of expanding one's skills or knowledge. (Kränzle & Schmid, 2018; Müller, 2018; Seeger et al., 2018). They are the leading contact persons in case of uncertainties and contribute to the empowerment and sensitisation of NMD-specific topics.

Care managers carry out training / consultations e.g. with Spitex services, long-term institutions, in-patient stays (for medical and nursing services) .

5.4 Area C: Professional development and networking

5.4.1 Subject development

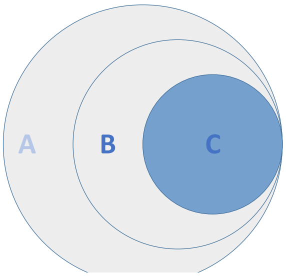


Figure 6: Services provided by care managers Area C: Professional development and networking

The professional development of a profession serves the further development, improvement of the quality of treatment and the increase of patient satisfaction. (Lindenhofgruppe, 2021).
The development of a specialist area is always necessary when complex symptoms, problems or medical conditions need to be treated. For example, specialised care services have developed in palliative care, which make it possible to promote interdisciplinary cooperation and reduce hierarchies. (Imhof et al., 2016).

Figure 6 shows the achievements in the area of professional development, which will be discussed below. NMD care managers contribute to development through engagement in the following areas:

- Regular professional exchange
- Participation in training and further education
- Evidence-based practice and participation in research & development projects
- Systematic research and critical appraisal of specialist literature
- Development of guidelines for action together with other professionals
- Participation in congresses and symposia

5.4.2 Networking

Networking, or networking in German, aims to promote the interconnectedness of a group of people with others. By networking among groups or families, they can find support and share problem-solving strategies. Professional networking among professionals promotes practice development and facilitates collaboration (Kaakinen et al., 2010).

NMD Care Managers contribute to the network through their involvement in the following areas:
- Networking with other care managers
- Networking with patient organisations
- Membership / participation in associations

This concept was developed as part of the Care-NMD-CH project and can be cited as follows: Waldboth, V., Nemecek, G., Bruschini, M., Hediger, H., Schuler, C., & Schubert, M. (2022). Concept for NMD care management. Project CARE-NMD-CH: Phase B. ZHAW Health. https://www.zhaw.ch/de/gesundheit/forschung/pflege/projekte/care-nmd-ch/

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Appendix 1: NMD Care Management Case History Form - Paediatrics

Date	
Abbreviation specialist	

Interlocutor	*With whom was the medical history taken?*
Patient	
Name	
Date of birth	
Language/ Origin	
Parents	
Siblings	
1. Contact	
Name	
Relationship to the patient	
Contact	Address:
	Phone:
	E-mail:
Social history	Relatives / Family: *Who all belongs to the family / who are important relatives of your child?*
	Housing situation: *What is your / their current living situation? Who all lives in the same household (e.g. siblings, grandparents)? Do you (respectively young affected persons) / does your child live in assisted living / in an institution? Are there stairs or a lift or other supporting installations? Is the flat barrier-free?*
	External support needs: *Do you / does your child make use of external support, e.g. from Kispex? If yes, which services are received and how often?*
	Education *Does your child go to nursery/school/? Which school/class does your child attend? Does your child complete an apprenticeship/study?*
	Activity *Do you / does your child claim IV benefits? Which IV benefits does your child claim?* *Are you employed as a dependent person? If yes, what is your workload?*
	Living will/ advance directive: *Do you / does your child have a living will or a health care proxy?*
	Transition *How independent are you / is your child? How are the detachment processes shaping up? How is the transition to adult care planned?*

Main diagnosis	*If known*
Medical history	Course of disease: *How has the disease progressed so far? Were there stable/unstable phases?*
	Medication: *Are you / is your child currently taking medication? If yes, which ones?*
	Allergies: *Are allergies known?*
	Vaccination status: *Are you / is your child vaccinated?*
	Noxae: *For young people: Do you smoke? Do you drink alcohol? Do you take drugs?*
	Inlets and outlets: *Do you / does your child have instillations of any kind (e.g. PEG tube, DK, PICC, Port-a-cath)?*
	Wounds: *Do you / does your child have a wound or a plaster somewhere on the body?*
	Current situation/main complaints: *What is most on your / your child's mind at the moment? What brings you / her to us today? What are the main complaints or symptoms at the moment?*
Patient history	Breathing: *Do you / does your child have breathing problems? Is your child dependent on respiratory support equipment (inhalers, CPAP)?*
	Movement: *Are you / is your child limited in movement (gross and fine motor skills)? If yes, to what extent (walking, climbing stairs, turning over in bed, straightening the bedspread)? Does your child use aids to move around (e.g. wheelchair)?*
	Personal hygiene and dressing: *Do you / does your child need support in personal hygiene and dressing? How are the skin conditions (intact, dry, scaly)?*
	Food and fluid intake: *Do you / does your child need support with food and fluid intake? How do you feed your child (breastfeeding, formula, depending on age)? Is there anything special about food intake (e.g. thickening agents for swallowing disorders)? Are there any foods that your child does not tolerate or does not like? Does your child take nutritional supplements (sip feeds, fortified foods, tube feeds)?*
	Excretion: *Are there problems with urination or defecation (constipation, diarrhoea, bedwetting)? Does your child wear nappies/liners (depending on age)?*

Body temperature:

Do you / does your child suffer from fever, temperature instability or excessive or reduced sweat production?

Safety/ Risks:

Are there any risks (falls, pressure sores, contractures)? Do you use aids to ensure a safe environment (alarm clock, paging system)?

Rest and sleep:

Are you satisfied with your / are you satisfied with your child's sleep? What is your child's sleep rhythm? Are there any special sleep rituals? What are the sleeping times? What calming rituals/offers do you give your child (depending on age, e.g. nuggi, swaddling, carrying)? Do you use sleep-inducing substances (depending on age, calming teas, valerian tincture, lavender)? Do you / does your child suffer from tiredness/fatigue during the day? What contributes to rest?

Keeping busy:

What are your occupations / hobbies? What is your child's play behaviour like? Does your child have favourite toys? Can your child occupy himself/herself (depending on age)? Do you / does your child have social contacts outside the family (friends)? Do you / does your child suffer from concentration difficulties?

Communication:

Do you / does your child have difficulties communicating verbally or non-verbally? Can you write independently (handwriting, depending on age)? Do you need aids to facilitate communication? Is your child's communication age-appropriate?

Development/ Sexuality:

Is your child's development age-appropriate? What are the developmental milestones (transition)? Is your child receiving hormone replacement therapy? For young people: Are you living in a partnership? Are you sexually active?

Finding meaning:

Do you belong to a religion? How do you and your relatives deal with your illness? How do you deal with your child's illness? What are important values for you? What gives strength in everyday life (spirituality, rituals, traditions)?

Care problems	*Insert nursing diagnoses if necessary*
Resources	

Goals

Measures

Interprofessional treatment team

Therapies and services	Physiotherapy: *Involved Yes/No? Frequency? Contact person?*
	Logotherapy: *Involved Yes/No? Frequency? Contact person?*
	Occupational therapy: *Involved Yes/No? Frequency? Contact person?*
	Psychology / Psychotherapy: *Involved Yes/No? Frequency? Contact person?*
	Early intervention/developmental support: *Involved Yes/No? Frequency? Contact person?*
	Nutritional counselling: *Involved Yes/No? Frequency? Contact person?*
	Social Services: *Involved Yes/No? Frequency? Contact person?*
	Swim training: *Involved Yes/No? Frequency? Contact person?*
	Companies for aids/ consumables/ medical devices *Involved Yes/No? Frequency? Contact person?*
Treatment team	Neurology: *Involved Yes/No? Frequency? Contact person?*
	Pneumology: *Involved Yes/No? Frequency? Contact person?*
	Cardiology: *Involved Yes/No? Frequency? Contact person?*
	Orthopaedics: *Involved Yes/No? Frequency? Contact person?*
	Paediatrician *Involved Yes/No? Frequency? Contact person?*
	Kispex *Involved Yes/No? Frequency? Contact person?*
	Palliative Care Team/Hospice: *Involved Yes/No? Frequency? Contact person?*

Mothers and fathers counselling *Involved Yes/No? Frequency? Contact person?*
Other services: *Involved Yes/No? Frequency? Contact person?*

This anamnesis form was developed within the framework of the concept phase B of the Care-NMD-CH project, taking into account the anamnesis grids of Anna Maria Sury, Centro Myosuisse Ticino and Mirjam Marti, Children's Hospital Zurich - Eleonorenstiftung as well as the ATLs' of Liliane Juchli. The following literature was included in the development: Diagnosis and Treatment of Duchenne Muscular Dystrophy: Family Guide (https://treat-nmd.org/wp-content/uploads/2019/11/uncategorized-Duchenne_Ratgeber.pdf); Palliative zh+sh: Working Tools (https://www.pallnetz.ch/arbeitsinstrumente.htm).

Appendix 2: NMD Care Management Case History Form - Adults

Date	
Name specialist	
Interlocutor	*With whom was the medical history taken?*
Patient	
Name	
Date of birth	
Language/ Origin	
Contact	Address:
	Phone:
	E-mail:
2. Contact	
Name	
Relationship to the patient	
Contact	Address:
	Phone:
	E-mail:
Social history	Relatives/ family: *Who do you count as your family/dependants?*
	Housing situation: *What is your current living situation? Do you live alone? Do you live in assisted living/institutional care? Are there stairs or a lift or other supportive installations? Is the flat barrier-free?*
	External support needs: *Do you use external support, e.g. from Spitex / personal assistance? If yes, which services do you receive and how often?*
	Marital status: *Are you single, married, divorced, widowed? Are you living in a partnership?*
	Activity: *Are you still at school, in an apprenticeship or studying? Are you employed? If yes, what is your workload? Do you receive a pension (AHV, IV)?*
	Living will/ advance directive: *Do you have a living will or a health care proxy?*
Main diagnosis	*If known*

Medical history	Course of disease: *How does your disease present itself? How has the disease progressed so far?*
	Medication: *Are you currently taking medication?*
	Allergies: *Do you have any known allergies?*
	Noxae: *Do you smoke? Do you drink alcohol? Do you take drugs?*
	Vaccination status: *What vaccinations have you had? Pay particular attention to flu vaccination and pneumococcal vaccination.*
	Inlets and outlets: *Do you have instillations of any kind? (e.g. PEG tube, DK, PICC, Port-a-cath)*
	Wounds: *Do you have a wound, bandages or a plaster anywhere on your body?*
	Current situation/main complaints: *What is on your mind most at the moment? What brings you to us today? What are your main complaints or symptoms at the moment?*
Patient history	Breathing: *Do you have breathing problems? Are you dependent on respiratory support devices (e.g. inhalers, CPAP, tracheostomy)? How much support do you need when using devices?*
	Movement: *Are you limited in your movement (gross and fine motor skills)? If so, to what extent (walking, climbing stairs, turning over in bed, adjusting the bedspread)? Do you use aids to move around (e.g. wheelchair, rollator)?*
	Personal hygiene and dressing: *Do you need help with washing or dressing? What are your skin conditions (intact, dry, scaly)?*
	Food and fluid intake: *Do you need support with food and fluid intake? Is there anything special about your food intake (e.g. difficulty swallowing)? Are you intolerant to certain*

	foods? Do you take food supplements (sip feeds, fortified foods, tube feeds)? How is your salivation?
	Excretion: *Do you have problems with urination or defecation? Do you wear pads? Are you prone to constipation or diarrhoea?*
	Body temperature: *Do you suffer from fever? Do you suffer from excessive or reduced sweat production?*
	Safety/ Risks: *Can you provide a safe environment? Do you use aids to ensure your safety (alarm clock, paging system)? Are there any risks (falls, pressure sores, contractures)?*
	Rest and sleep: *Are you satisfied with your sleep? Are you able to sleep through the night? Do you use sleep-inducing substances (calming teas, valerian tincture, lavender)? Do you suffer from tiredness/fatigue during the day?*
	Keeping busy: *How do you organise your free time? What do you enjoy doing? Do you suffer from concentration problems? Are you able to maintain friendships and acquaintances? What do you do for recreation?*
	Communication: *Do you have difficulties communicating verbally or non-verbally? Can you write independently (handwriting)? Do you need aids to facilitate communication?*
	Feeling like a woman or a man/ sexuality: *How do you feel about your body image? Do you live in a partnership? Are you sexually active? Do you take hormone replacement therapy?*
	Finding meaning: *Do you belong to a religion? How do you and your relatives deal with your illness? What are important values for you? What gives you strength in everyday life (spirituality, rituals, traditions)?*

Care problems	*Insert nursing diagnoses if necessary*
Resources	

Goals	
Measures	
Interprofessional treatment team	
Therapies and services	Physiotherapy: *Involved Yes/No? Frequency? Contact person?*
	Logotherapy: *Involved Yes/No? Frequency? Contact person?*
	Occupational therapy: *Involved Yes/No? Frequency? Contact person?*
	Psychology / Psychotherapy: *Involved Yes/No? Frequency? Contact person?*
	Nutritional counselling: *Involved Yes/No? Frequency? Contact person?*
	Social Services: *Involved Yes/No? Frequency? Contact person?*
	Swim training: *Involved Yes/No? Frequency? Contact person?*
	Companies for aids/ consumables/ medical devices *Involved Yes/No? Frequency? Contact person?*
Treatment team	Neurology: *Involved Yes/No? Frequency? Contact person?*
	Pneumology: *Involved Yes/No? Frequency? Contact person?*
	Cardiology: *Involved Yes/No? Frequency? Contact person?*
	Orthopaedics: *Involved Yes/No? Frequency? Contact person?*
	Family doctor *Involved Yes/No? Frequency? Contact person?*
	Spitex/ Home help *Involved Yes/No? Frequency? Contact person?*
	Palliative Care Team/Hospice:

Involved Yes/No? Frequency? Contact person?

Other services:

Involved Yes/No? Frequency? Contact person?

This anamnesis form was developed within the framework of the concept phase B of the Care-NMD-CH project, taking into account the anamnesis grids of Anna Maria Sury, Centro Myosuisse Ticino and Mirjam Marti, Children's Hospital Zurich - Eleonorenstiftung as well as the ATLs' of Liliane Juchli. The following literature was included in the development: ALS-FRS-R, German version (https://www.encals.eu/wp-content/uploads/2017/12/ALSFRS-R-German-version.pdf); Palliative zh+sh: working tools (https://www.pallnetz.ch/arbeitsinstrumente.htm).