



CENTRO CLINICO
Nemo
ANCONA



CHARTER OF SERVICES NEMO ANCONA



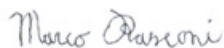
Dear Friend,

with this Charter of Services you have the opportunity to learn about the main services that Centro Clinico NeMO makes available for people suffering from neuromuscular

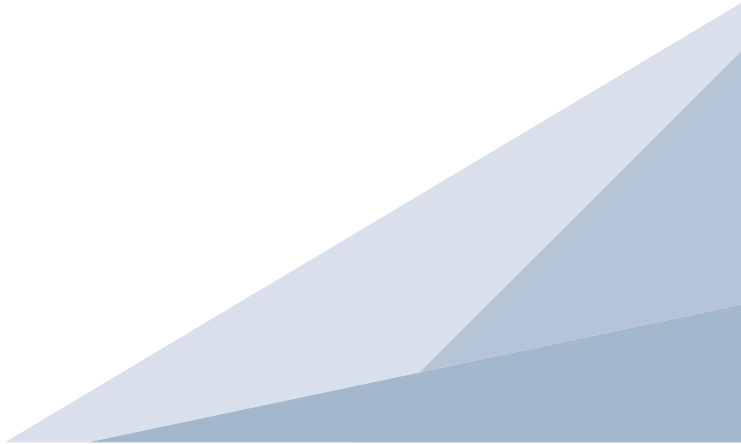
diseases and their families.

For any clarification or advice, our medical, nursing, rehabilitation and administrative staff will be at your complete disposal at the facility, but also by phone and by e-mail.

We will also be happy to welcome any suggestions, useful for improving our service and responding to your needs.

A handwritten signature in dark ink, reading "Marco Rasconi".

Marco Rasconi
President of Centri Clinici NeMO



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THE CHARTER OF SERVICES

The Service Charter is the document that Italian law introduced as part of the innovation of relations between institutions and citizens, to guarantee the quality and the ways in which the services are provided. In particular, in the health sector, it is the tool that protects the citizen's right to health.

This guide aims to offer all the necessary information on the clinical services offered and on the model of assistance adopted by the NEMO Clinical Center.

The NeMO Center adopts the fundamental principles, sanctioned by the Directive of the President of the Council of Ministers of 27 January 1994 and the Decree of the President of the Council of Ministers of 19 May 1995, relating to:

IMPARTIALITY

Attitudes of partiality and injustice, i.e. non-objective treatments towards users, must be avoided.

CONTINUITY

The service must be ensured on a regular and continuous basis except in cases where abstentions from it are regulated or officially announced by law or fall within the organizational aspects of the service.

RIGHT OF CHOICE

The user can freely choose the health facility to which he wishes to access on the national territory.

PARTICIPATION

The information, personalization and humanization of the service is ensured, protecting the User within the public health system.

EFFICIENCY AND EFFECTIVENESS

The organization and provision of services conform to criteria of efficiency and effectiveness.

WHO IS IT FOR?

The main recipients of the Service Charter are citizens who are users of the National Health Service, health professionals, general practitioners and voluntary associations and associations for the protection of citizens' rights.

WHAT IT'S FOR?

The Service Charter is not a simple means of consultation, but a complete information tool on all the services offered by the NEMO Center, so that the user can know how to access it. The main purpose is to guarantee users full respect for their rights and, as patients, the utmost dignity. In this spirit, the user is requested to examine the information contained in our "Service Charter" by offering us his / her collaboration, presenting any observations or suggestions aimed at achieving a further improvement in the quality of assistance.

RIGHTS AND DUTIES OF PATIENTS

RIGHT TO INFORMATION

The patient has the right to obtain from the health facility all the information relating to the services provided, the methods of access and to receive complete and understandable information about the diagnosis, treatment and prognosis of his disease. He has the right to be able to immediately identify the people who are treating him.

INFORMED CONSENT

It represents a way in which the patient exercises the right to information and makes the medical act on his person lawful. Except in cases of urgency, in which a delay can lead to a danger to life, the patient, before undergoing diagnostic or therapeutic procedures, has the right to receive all the necessary information to express an effectively informed consent.

RIGHT TO CONFIDENTIALITY

The patient has the right that the information regarding his / her state of health and any other personal information are subject to the constraint of confidentiality, required of health and non-medical personnel. The use of patient personal data by the facility is governed by the "privacy law". The data controller is the Serena ETS Foundation. In compliance with GDPR 679/2016, specific information on the protection of patients' personal data is provided at the premises of the facility. In compliance with Legislative Decree 196/2003 and subsequent amendments, specific information relating to the processing of patients' personal data is also provided.



RIGHT TO PROPOSE COMPLAINTS AND SUGGESTIONS INTERNAL REGULATION

ART. 1

At the NEMO Clinical Center pursuant to art. 14 paragraph 5 of the D.L. 502/92 modified by D.L. 517/93, the complaints service is activated which allows you to:

1. Receiving observations, oppositions or complaints in an administrative way, submitted by the subjects, pursuant to art. 2 of these provisions;
2. Provide a timely response to the complainant by the Management;
3. Provide the complainant with all the information and anything else necessary to ensure the protection of the rights recognized by the relevant legislation in force;
4. Prepare, when he could not eliminate the cause of the complaint, the response signed by the Management in which it is declared that the aforementioned conclusions do not prevent the judicial proposition pursuant to art. 14 paragraph 5 of the D.L. 502/92 modified by D.L. 517/93.

ART. 2

All users, relatives or similar, as well as the managers of the Voluntary and Protection Bodies, accredited by the Marche Region are entitled to the acts referred to in the paragraph of the previous article.

ART. 3

The subjects identified in art. 2 may exercise their right by submitting observations, objections or complaints within 15 days, from the moment in which the interested party has become aware of the act or behavior against which they wish to oppose, through:

- Letters on plain paper, addressed and sent to the Administrative Department and delivered to the Health / Clinical Department.
- A specific Complaint Form, available at the reception.

DUTIES OF THE SICK

Guests have the duty, in compliance with the internal regulations of the structure, to maintain a responsible and correct attitude towards other patients, staff, environments and equipment.

Guests also have the duty to respect the work and professionalism of health workers, as an indispensable condition for implementing a correct therapeutic and assistance program.

The patient is required to respect the ban on smoking: compliance with this provision is an act of acceptance of the presence of others and a healthy personal lifestyle to be maintained in the structure, before being a legal obligation (Article 51, paragraph 2 of the law of 16 January 2003, n.3 and subsequent amendments). The patient has the right to correct information on the organization of the health facility, but it is also his duty to exercise this right in the appropriate time and in the appropriate places.

ACCIDENT SAFETY

Accident prevention conditions are guaranteed by scrupulous compliance with national regulations, with particular reference to Legislative Decree 81/2008 and regional ones. All personnel are informed about the content of the safety and evacuation plans and related updates. Special signs indicate the risks and prohibitions present in the structure.

— QUALITY

The improvement of the quality of the service is a continuous process that concerns the whole structure that is committed to work to provide its patients with a service that is increasingly suited to the needs of an evolving society. This happens, on the part of the NeMO Clinical Center, through a culture oriented to the "patient" and to a valid organization of services.

IL CENTRO CLINICO NEMO (NEUROMUSCULAR OMNICENTRE)

The Ancona NeMO Clinical Center is a multifunctional structure capable of:

- o Respond specifically to the rehabilitation, care and assistance needs of those suffering from neuromuscular diseases;
- o Intervene with the most suitable means to provide effective global management of the person with neuromuscular disease, at any age and at every stage of the disease.

The NeMO Clinical Center was born from the far-sightedness of the major national associations of patients with neuromuscular disease, which have given life to a treatment project that puts the needs of the person and his family at the center.

At NeMO everything revolves around the person, thanks to a multidisciplinary care model, which integrates professional and interdisciplinary skills, to offer complete and seamless care, creating targeted rehabilitation programs with high specialization and specific to the needs of each patient.

The organizational and partnership model of the NeMO Clinical Center is based on the synergy between the private social sector and the local hospitals. This type of partnership represents an innovative and sustainable formula, which allows the mission of the NeMO Center to be achieved, as it is located within established governance structures and systems.

NeMO represents an example of horizontal subsidiarity, where the requests of those close to the patients' needs generate value for the entire system, in a perspective of co-responsibility with the institutions, in the composition of the overall offer of services.

The NeMO Clinical Center is the project of the Serena ETS Foundation, a private law participation foundation made up of six members/partners.

PARTNERS

UILDM - UNIONE ITALIANA LOTTA ALLA DISTROFIA MUSCOLARE

UILDM is the national association of reference for people with dystrophies or other neuromuscular diseases. It was born in 1961 and aims to promote scientific research and health information on neuromuscular diseases and the social inclusion of people with disabilities. The Association is present throughout the national territory with 64 Sections that carry out wide-ranging social work and medical-rehabilitative assistance, managing in some cases outpatient centers for rehabilitation, prevention and research, in close collaboration with university and social structures basic health care.

www.uildm.org

FONDAZIONE TELETHON

Telethon Foundation is one of the main Italian biomedical charities, founded in 1990 on the initiative of a group of patients suffering from Muscular Dystrophy. Its mission is to arrive at the treatment of rare genetic diseases through scientific research of excellence, selected according to the best practices shared at an international level. Through collaboration with public health institutions and pharmaceutical industries, the results of the research have been translated into therapies accessible to the patient, contributing to an overall advancement of the research.

www.telethon.it

AISLA APS - ASSOCIAZIONE ITALIANA SCLEROSI LATERALE AMIOTROFICA

AISLA APS was founded in 1983 with the aim of promoting information on the disease and stimulating the competent structures to provide adequate and qualified care of the sick.

Today it is the national reference body for the protection, assistance and treatment of ALS patients, has 64 territorial representatives in 19 Italian regions and 2,412 members. Thanks to the work of 250 volunteers, the association offers concrete support to patients and family members, through a widespread presence on the territory, in synergy with national and international organizations and with health institutions. AISLA's work is concentrated in four areas of activity: information, assistance, research and training.

www.aisla.it



ASSOCIAZIONE FAMIGLIE SMA APS ETS GENITORI PER LA RICERCA SULL'ATROFIA MUSCOLARE SPINALE

Famiglie SMA is an association made up of parents of children and adults suffering from Spinal Muscular Atrophy. Established in 2001 and active throughout Italy, it is currently the main association of reference for those involved in SMA. It is a network of support and constant information for all patients and those close to them, supporting them psychologically; and a reference point for medical and regulatory news. It fights to support scientific research and to obtain legislative measures in favor of the sick.

www.famiglie.sma.org



SLANCIAMOCI ASSOCIAZIONE NON PROFIT

Slanciamoci is a non-profit association that has the primary objective of contributing to the development of research on degenerative neuromuscular diseases, with particular reference to ALS, through the organization of events and musical evenings aimed at raising funds. Through the donations collected, Slanciamoci contributes to support the NeMO Clinical Center in conducting research projects on ALS, aimed in particular at understanding the role of genetic factors within this pathology.

www.slanciamoci.it



FONDAZIONE VIALLI E MAURO PER LA RICERCA E LO SPORT ONLUS

The Vialli and Mauro Foundation for Research and SportOn-lus, founded in 2003, works with the aim of allocating funds to medical scientific research on Cancer and Amyotrophic Lateral Sclerosis (ALS). At the base of the Foundation's activities are the love of life, the desire to act concretely and to always be transparent. Thanks to the generosity of partner companies and private individuals, who supported it at the events and various activities promoted, it was possible for the Foundation to main-tain a strong synergy with realities that represent excellence in the field of scientific research. This is one of the reasons why, as a form of guarantee, Gianluca Vialli and Massimo Mauro have cho-sen to put their names in the Foundation's header.

www.fondazionevialliemauro.org

MISSION AND OBJECTIVES

The mission of the NEMO Clinical Center is to provide highly qualified assistance which, through a multidisciplinary team, offers the utmost attention to the person and to the totality of their care needs, through specific attention to the quality of the relationship between the assistant and the assisted person, until the understanding and trust necessary to instill in the patient the sense of security and serenity which, in themselves, are an element of quality of life.

— STRUCTURE

The NEMO Ancona Clinical Center, part of the "Ospedali Riuniti" University Hospital of Ancona, meets the most modern organizational, technological and quality requirements. Built on the fifth floor of body C, the center is spread over 880 square meters and has 12 ordinary hospital beds code 75 and 56, of which 2 for pediatric patients, 2 Day Hospitals (6 double rooms and 2 single rooms).

Specific spaces have been created for elective activities, in particular a clinic dedicated to the management of respiratory disorders. The department has a gym dedicated to the rehabilitation of patients, with dedicated spaces for adults and for the pediatric age. Inside it has a living room for adults and a pediatric stay to encourage moments of leisure and aggregation and a space

rc



**12 ordinary hospital beds
(of which 2 for pediatric patients)**

**2 Day Hospital
(6 double rooms and 2 single rooms)**



— TAKING CHARGE

Neuromuscular pathologies are characterized by the involvement of several organs and systems, which require the involvement of various specialists, who must integrate and interact with the entire professional team, in order to set up a single individual rehabilitation project and a shared therapeutic program.

For this reason, the NeMO Clinical Center is based on a model of management for neuromuscular diseases, specific and without discontinuity for every aspect of the patient's disease experience, based on the concept of omniservice:

- o each operator who intervenes in the treatment process is responsible for the overall result;
- o all the necessary specialist skills are available to the patient in a single access point (point of care approach);
- o a multidisciplinary team that shares information and responsibilities in the project of taking charge of each patient;
- o close integration between care, assistance and research;
- o continuity of the clinical-assistance path through personalized and programmed care plans with all levels of assistance;
- o presence of a nurse coach who supports families in managing daily problems and also acts as case manager;
- o continuity between research and clinical practice to offer patients the most innovative therapeutic solutions.

LOCATION AND MEANS OF TRANSPORT

The NeMO Ancona Clinical Center is located within the University Hospital of Ospedali Riuniti in Ancona. It is possible to reach the Clinical Center:

BY TRAIN FROM ANCONA STATION:



- At the exit of the train station, take BUS 30 which leads directly to the hospital square. It is also possible to use any bus that transits the state road northbound.
- From the Torrette railway station, use the SHUTTLE BUS 35 (terminus on the sidewalk opposite) which arrives at the hospital entrance.

BY CAR



FOR THOSE ARRIVING FROM THE ANCONA NORD MOTORWAY EXIT:

Take the SS16 towards Ancona and exit at Torrette. The hospital is located on the road that leads to Via Flaminia (Via Conca), on the right hand side.

FOR THOSE ARRIVING FROM THE ANCONA SUD MOTORWAY EXIT:

Take the exit for Ancona. Arrived at the Ancona Centro / Pesaro junction, continue towards Pesaro. Take the SS16 and exit at Torrette. Continue along the road (via Conca) which leads to Via Flaminia. The hospital is on the right side of the road.

SERVICES AND METHOD OF DELIVERY

NeMO Ancona Clinical Center is a rehabilitation facility, with three care regimes:

ADMISSION IN ORDINARY STAY

HOSPITALIZATION IN DAYTIME ACTIVITY

OUTPATIENT SPECIALIST ACTIVITY

THE SERVICES PROVIDED BY NEMO ANCONA CLINICAL CENTER ARE:

- Clinical-assistance and rehabilitation activities
- Individual and family psychological care
- Care-giver education and training
- Accompanying services for access to centers of excellence in their territory of origin and for the provision of home care
- Training activity
- Moments of training

**All activities are provided through the S.S.N.
(Italian National Health Service)**

HOSPITALIZATION

During hospitalization, medical assistance–rehabilitation services are performed aimed at ensuring an organic and appropriate therapeutic and rehabilitative intervention.

The patient undergoes an evaluation subjected to examinations of the clinical–functional conditions through instrumental and validated scales for the realization of the Individual Rehabilitation Project and to respond to his clinical and care needs.

DH DAY HOSPITAL

The Day Hospital is dedicated to patients who do not require hospitalization in the ordinary regime but who require clinical observation that is not compatible with simple outpatient evaluation. During the Day Hospital, a clinical functional assessment is performed and an Individual Rehabilitation Project is planned and health services of a rehabilitative nature and diagnostic analysis of a particular nature or complexity of execution are carried out.

MULTI-SPECIALIST ACTIVITIES IN THE OUTPATIENT OFFICE

The outpatient services of the NeMO Ancona Clinical Center include specialist visits in:

PHYSICAL MEDICINE AND REHABILITATION

PNEUMOLOGY

NEUROLOGY

PSYCHOLOGY

INFANT NEUROPSYCHIATRY

MULTIDISCIPLINARY PERFORMANCES

GENERAL INFORMATION AND ACCESS PROCEDURES

The NeMO Clinical Center welcomes, in ordinary hospitalization and Day Hospital, patients with neuromuscular diseases from acute wards who require multidisciplinary care and an individual rehabilitation project and patients who, coming from home, present a decay clinical-functional conditions, for a multidisciplinary re-evaluation and the definition of rehabilitation objectives.

To access the services of the NeMO Ancona Clinical Center as the first access, the patient must be in possession of the referral from the attending physician. A clinical report is also required that indicates the need for multidisciplinary and rehabilitation management.

Based on the medical history and the documentation presented, the multidisciplinary team takes care of the patient and formulates the individualized path to be carried out in ordinary hospitalization or in day hospital.

Outpatient visits can be booked by:

- calling the secretariat of the NeMO ANCONA Clinical Center on +39 071.5965960
- calling the CUP of the Marche Region by calling the free toll-free number 800.098798 from the landline or from the mobile network +39 0721.1779301 (costs to be paid by the user), with a referral by the attending physician (neurological visit, physical and rehabilitative medicine visit, pulmonology visit).

TIMETABLES AND ADDRESSES

For any information regarding NeMO Ancona Clinical Center and how to access the care pathway, you can contact the Reception offices:



**Monday to Friday
from 9.00 to 17.00**



**071.596 5960
071.596 5970**



**www.centroclinionemo.it
infonemoancona@centroclinionemo.it**

NECESSARY FOR HOSPITALIZATION

At the time of admission, the patient must present himself at the Reception on the 5th floor of the main entrance of the Torrette Hospital in Ancona for the completion of the administrative acceptance phase and the preparation of the medical record.

At the time of entry, the User must be equipped with:

- o Identity document and tax code Tessera sanitaria
- o Health insurance card
- o Any clinical documentation relating to the period prior to admission (medical records, radiographs, analyzes, prescriptions of therapies carried out and other diagnostic tests already carried out)
- o Effects necessary for personal hygiene
- o Comfortable clothing for rehabilitation activities

RESIGNATION AND ACCOMPANIMENT

At the time of discharge, the patient will be issued a report with the attachments relating to the conclusions and suggestions of the individual specialists.

In addition, the patient and / or his / her family will be provided with information regarding the centers of excellence present in their territory of origin, to which they can contact in case of acute disease.

Upon discharge, you are reminded, leaving the room, not to forget your personal effects and to carry out any administrative procedures at the acceptance office. If the user asks to be discharged against the opinion of the Healthcare professionals, he will be obliged to sign a declaration that relieves the structure of any liability caused by this decision.

In the event of non-compliance with the behavioral rules provided by the NeMO Clinical Center, the patient may be discharged as the trust relationship between doctor and guest at the basis of any therapeutic activity has ceased. For the return home, the user will have to provide for himself.

MEDICAL RECORDS

A copy of the full medical records is available within 30 days of the request, subject to a fee of €23.00.



All the information and the application form can be found on the website

www.centroclinionemo.it – Centro Nemo Ancona – transparent administration

You can also request a copy of your medical records:



071 596 4134
Monday to Friday: 9.30 – 11.30



cartellecliniche@ospedaleiriuniti.marche.it

THE OPERATORS OF CENTRO NEMO ANCONA



GENERAL MANAGER

He is an administrative manager who oversees the ordinary management of the Foundation in all areas in which it carries out its activities (health, social health, research) with the collaboration of managers, supervisors and employees in general, already employed by the Foundation itself, as well as consultants expressly appointed with the right to delegate part of their powers to qualified collaborators.



HEALTH DIRECTOR

He is a health manager, specialized in sanitary hygiene who deals with health management with the following functions and responsibilities:

- guarantor of healthcare for patients

- coordination of the health staff of the facility
- hygienic, sanitary and functional supervision of environments, devices and equipment
- supervision of the correct storage of drugs and devices
- control over compliance with mandatory reports
- control over the organization of the logistics of patients, visitors, suppliers
- quality control of the health documentation produced
- control over the correct disposal of waste

MANAGING DIRECTOR

He is an administrative manager who organizes, directs and controls the execution of the work of the Central Accounting and Management Control Office, the Goods and Services Purchasing Office and the Fundraising Office.

CLINICAL DIRECTOR

He is a second level medical manager, responsible for the organization of the Health Services and the staff dedicated to them in the context of the reception activities in ordinary and day hospitalization and on an outpatient basis, in the context of diagnostic / therapeutic / assistance and rehabilitation paths.

SPECIALIST DOCTORS

They are 1st level medical managers, specialists of the various disciplines, who ensure the relative support, in the diagnostic phase, in the definition of the treatment plan and in the definition of the therapeutic plan.

PSYCHOLOGISTS

They ensure a specialized psychological support service to users and family members.

ASSISTANCE AREA COORDINATOR

He is responsible for coordinating assistance and rehabilitation in the ward and in the day area; organizes the procurement of drugs and consumables. Ensures the sanitation of the environments. It constitutes the reference for Care-Givers and patients. Collaborate with medical staff.

REFERENT OF THE REHABILITATION AREA

It depends hierarchically on the Assistance Area Coordinator and collaborates with her for the organization of rehabilitators in the ward and for the supply and proper management of the aids necessary for carrying out these activities.

NURSES

They are responsible for nursing care for the patient, carry out educational and relational interventions. They collaborate with the Care Area Coordinator and the rest of the team.

TERAPISTI DELLA RIABILITAZIONE

They are responsible for rehabilitation services.

They are:

- MOTOR PHYSIOTHERAPIST
- RESPIRATORY PHYSIOTHERAPIST
- OCCUPATIONAL THERAPIST
- THERAPIST OF NEURO AND DEVELOPMENTAL PSYCHOMOTRICITY
- SPEECH THERAPIST

SOCIAL HEALTH WORKERS (OSS)

They assist the patient with regard to personal hygiene, mobilization, meal administration. They collaborate with the Care Area Coordinator and the rest of the team.



ADMINISTRATIVE COORDINATOR

The Administrative Coordinator is responsible for organizing and coordinating the activities carried out by the administrative staff;



UFFICI CENTRALI DI DIREZIONE

- HEALTHCARE COORDINATION OFFICE
- MANAGEMENT AND HUMAN RESOURCES DEVELOPMENT OFFICE
- TECHNICAL OFFICE AND INFORMATION SYSTEMS
- GENERAL AFFAIRS AND COMPLIANCE OFFICE QUALITY OFFICE
- GOODS AND SERVICES PURCHASING OFFICE
- ACCOUNTING AND MANAGEMENT CONTROL DEPARTMENT
- FUNDRAISING OFFICE
- COMMUNICATION OFFICE
- SCIENTIFIC RESEARCH
- PUBLIC RELATIONS OFFICE (URP)



SITRA

Nursing, technical and company rehabilitation service, in staff with the Health Department, defines the need for human and material resources and promotes organizational well-being by investing in the improvement of communication and conflict management. Manages the nursing/rehabilitation coordinators of the Nemo Centers and collaborates with the coordinators themselves in the management and organization of the nursing, rehabilitation, technical and social assistance staff. SITRA favors the conditions for increasing the motivation and responsibility of professionals, promoting professional development in line with the profiles of the operators. Periodically collects the training needs for the implementation of significant and coherent activities for organizational growth.

REGISTERED OFFICE

Fondazione Serena ETS - Centri Clinici NeMO

Piazza Ospedale Maggiore, 3 - 20162 Milano

C.F. e Partita IVA 05042160969

Phone +39 02.91.43.371 | Fax 02.91.43.37.200

www.centrocliniconemo.it | info@centrocliniconemo.it





CENTRO CLINICO

Nemo