

rondom

a unique health care
institution for people with
multiple sclerosis

nieuw unicum



A collection of articles from Rondom MS, issued by Stichting MS Research

Admiration

All ill people want to get better. But what do you do if you know that it will never happen, that you will not recover from an illness that is literally and figuratively nerve-racking, because there is unfortunately no cure? You set your sights on an improved quality of life and live your life as fully as possible, focusing on what you can do, and how you can do it, in spite of your illness. After all, you don't want to be exclusively defined by 'illness' – that is not what is most important about you and does not make you who you are.

That is the basic principle behind the care provided by our colleagues at Nieuw Unicum: passionate, engaged, warm. This principle goes hand in hand with their expertise. They apply the knowledge acquired over many years of experience treating people with progressive MS and other illnesses in optimal and innovative ways for the benefit of all – not just for the people staying at Nieuw Unicum, but also those being treated at home. To this end, Nieuw Unicum's professional staff collaborate closely with various other care providers throughout the Netherlands. They also carry out scientific research into treatment methods in order to acquire new and improved knowledge with which to help people with MS.

Nobody wants to be ill. Nobody wants to become ill. Nobody wants to be dependent on treatment. That goes for me as well. However, if anything should happen to me, I know that I would like to receive treatment for my illness at Nieuw Unicum, where I will be treated as a human being. I have a great deal of respect and admiration for the people who stay there as well as for the people who work there.

Dorinda Roos
Director, Stichting MS Research



CONTENTS

- 3** An institution with a remarkable ethos
- 5** 'Nearby if possible, remotely if required'
- 8** Expertise is a verb

ABOUT THIS MAGAZINE

This one-off issue of Randon Nieuw Unicum was made possible by Stichting MS Research. It combines articles about Nieuw Unicum that previously appeared in Randon MS, the magazine of Stichting MS Research.

Impression: 500 copies

Design: Pre Press Buro Booi, Maarsbergen

Production: Regalis, Zeist

Photos: archive of Stichting MS Research and Nieuw Unicum

Contact:



Zandvoortselaan 165
 2042 XK Zandvoort
 The Netherlands
 Telephone: +31 (0)23 5761212
www.nieuwunicum.nl
info@nieuwunicum.nl



Leidseweg 557-1
 PO Box 200
 2250 AE Voorschoten
 The Netherlands
 Telephone: +31 (0)71 5600500
www.msresearch.nl
info@msresearch.nl

*Cover photo: Ada and Maarten Boon.
 Maarten has been staying at Nieuw Unicum
 for five years.*



Klaar Valkhoff receives walking instruction from physiotherapist Emilie Geerts in the gymnasium.

An institution with a remarkable ethos

Very occasionally, you come across a health care institution where it is immediately apparent that what matters most is not the organisation (i.e. the institution), but the attitude – in other words, the ethos.

Nestling among the Zandvoort dunes, near the villas of Aerdenhout and Bentveld and next door to the exclusive Kennemer Golf & Country Club, Nieuw Unicum is a health care institution with a caring ethos.

Care for advanced-stage patients

Nieuw Unicum is fully alive to the needs of people who suffer from decreasing mobility. Its mission is to offer people who have passed the initial stage of decreased mobility the care they desire at that moment. Nieuw Unicum offers professional care to people who suffer from complex physical impairments as a

result of neurological or other disorders (e.g. multiple sclerosis, Parkinson's disease, stroke/CVA). With regard to MS, particularly advanced MS, Nieuw Unicum houses a centre of expertise specialising in symptoms including loss of cognitive and speech abilities, dysphagia and spasticity. Thanks to years of experience treating people with MS, Nieuw Unicum's staff are able to assess the range of activities that people are still capable of, even when their MS can no longer be treated medically.

Staying at the main site...

Nieuw Unicum offers a wide range of in-house activities to its clients:

- accommodation on the basis of 24/7 intramural care (i.e. inpatient care on medical grounds);
- (para)medical treatment;
- (neuro)psychological treatment and care;
- work-related, educational or recreational daytime activities.

Clients are offered care, services and daytime activities on the basis of individual care plans. Nieuw Unicum's main site on Zandvoortselaan in Zandvoort caters to people with physical and/or cognitive impairments who require 24/7 intramural care. At the time of writing, this group comprises almost 250 people, of whom 142 have MS.



MS Remote Care allows people with MS to contact Nieuw Unicum's professionals from the comfort of their own home.

... or nearby

Patients who require less intensive levels of care can comfortably stay at one of three subsidiary locations in Zandvoort and Haarlem. For those who fall in between categories, there is 'Union' care: independent living in completely adapted accommodation, with all the facilities of the main site close by and the security of 24/7 care if needed – a type of made-to-measure sheltered housing.

Recharging your batteries in Zandvoort

Caring for partners or loved ones with MS can be draining for the carer, to the point of becoming overwhelming for both the carer and the patient. What could be better in this case than seeking refuge at this beautiful retreat in the dunes a couple of times a year, for one or several weeks at a time? This type of short stay is a great way to 'recharge your batteries', as the saying goes. It is an ideal combination, in that it provides a bit of breathing space for both the client and the carer. Meanwhile, the client has the opportunity to consult Nieuw Unicum's various experts in a short amount of time. This gives the carer a chance to relax, so that both parties can effectively manage the next period.

Personal contact from your own home

Nieuw Unicum is striving to also make its expertise accessible to the more than 6,000 people with advanced MS who live farther afield in the Netherlands. For this group, regular site visits are often impractical or even impossible, much as they would welcome the opportunity to discuss their case with a specialist and experienced MS nurse or other medical professional. Nieuw Unicum's MS Remote Care service, an online coaching programme primarily aimed at people with MS who live in their own home, has been designed with this target group in mind. A secure Skype VoIP connection allows the client and the health care provider to see and talk to each other as if they were face-to-face. This has turned out to be an ideal supplement to regular treatment and care. Patients can speak freely with experts at a time of their convenience, without having to worry about such matters as transport. Behind this official description lies a world of attention, guidance, support and care, designed to offer a humane existence to a group of highly vulnerable Dutch clients. MS Remote Care can be regarded as a fully-fledged consultation service that offers targeted help, thanks to a written questionnaire completed by the client beforehand, which allows the health care provider to prepare for the consultation. Clients can view the answers to the questionnaire and the advice provided during consultations in their own personal online file. With this information at their disposal, clients find it easier to remain in control of their own lives.

A clear mission

Now approaching its 50th anniversary, Nieuw Unicum has built up a wealth of



Interactive cycling trips are a godsend to those who are no longer able to cycle themselves.

knowledge and experience. In spite of its modesty, Nieuw Unicum's reputation as a specialist institution is more than deserved.

Who knows the advanced MS patient inside out?

Who can recognise a cough or two after dinner as a sign of dysphagia? Who understands that people who appear well-fed can still be malnourished? Who picks up on the fact that people have a hot meal for lunch because their energy levels drop to such an extent in the afternoon that they are unable to eat a hot meal for dinner?

Nieuw Unicum's professionals do. It might be second nature to them, but it's hardly something just anyone can do.

To really know and understand people with MS is a highly specialist skill that Nieuw Unicum's staff have mastered. ●

randon nieuw unicum

If you are curious about Nieuw Unicum and want to find out what they can do for you, contact Fred de Wit by emailing fdewit@nieuwunicum.nl or calling +31 (0)23 5761139. He can also tell you more about referrals, indications and which costs are covered by your health insurer.



Tilting platforms for wheelchairs at dental surgeries allow people who are wheelchair-bound to be treated in their wheelchair, rather than having to make the exhausting transfer to the dentist's chair.

Sharing knowledge, boosting the quality of care

‘Nearby if possible, remotely if required’

A developing organisation

Ongoing development is the hallmark of Nieuw Unicum, a skilled, deliberate, capable and inquisitive organisation that is undergoing a measured transition from a traditional local and regional institution, offering care and support to people with serious and permanent physical and mental impairments, to a centre of expertise that is also designed to share specialist knowledge, expertise and skills.

Expertise

The Netherlands is home to around 6,000 people with a rapidly progressing form of multiple sclerosis who are not yet receiving suitable care, which is to say that they are not receiving multidisciplinary care. As neurologists and revalidation physicians are often unable to provide any further help, this group is generally considered to have exhausted all available treatment. However, this does not mean that these people no longer have the same quality of

life requirements as other people, whether these requirements relate to living and/or working conditions, education, leisure, health, lobbying, social contacts, duties or responsibilities. Nieuw Unicum's specialist care is largely targeted at this group, and it knows like no other institution what it takes to make people with MS live their lives to the full. Nieuw Unicum not only uses this expertise to care for patients at its main site in Zandvoort, but also shares it with colleagues throughout the country. This



Participation is one of Nieuw Unicum's main points of focus.

allows this large group of around 6,000 people to benefit from improved care, which in turn contributes to a dignified and independent life.

Specialist care

At its core, Nieuw Unicum wants to help reduce fragmentation in the area of care and support for people with MS. In Nieuw Unicum's opinion, one of the causes of this fragmentation is an insufficient awareness of the fact that people with MS, particularly those with its most rapidly progressing form, require highly specialist care – and specialist care requires specialist knowledge.

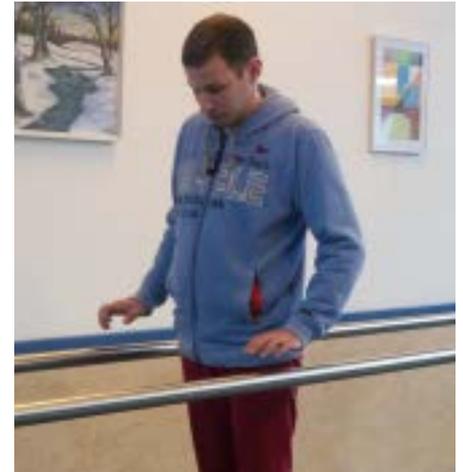
The Multidisciplinary Screening (MdS), a 'periodic inspection' with advice for people with MS

MS manifests itself in unpredictable ways and in a wide variety of guises, and can affect every conceivable bodily function. For this reason, the only effective treatment approach is a multidisciplinary one. At Nieuw Unicum, MS patients with complex

symptoms who have been referred by a GP or specialist can be examined by one of Nieuw Unicum's multidisciplinary teams. This often takes no more than a day, which minimises the need for travel. Alternatively, it can take place during a short stay at Nieuw Unicum. Thanks to this multidisciplinary approach, Nieuw Unicum is able to issue genuinely integral and up-to-date care, support and/or treatment advice to the regular health care provider, so that MS patients can continue to be treated in familiar surroundings and continue their daily lives in the comfort of their own homes. Nieuw Unicum regards the Multidisciplinary Screening as an opportunity to contribute to maintaining the patient's independence – nearby if possible, remotely if required.

Remotely accessible

Thanks to MS Remote Care, Nieuw Unicum's specialist knowledge is available immediately, permanently and nationwide. This online service can be accessed on working days by those who require specific, tailor-made MS advice. MS



Yorick van der Vlugt practices a parallel bar exercise.

Remote Care is a modern service designed for the convenience of people with MS. Clients can contact Nieuw Unicum from their desktop computers or mobile devices, such as tablets or mobile phones, so that they don't need to leave the house – the advantages of this are inconceivable to those who have no personal experience of the burden of MS. At Nieuw Unicum, MS Remote Care has been organised in such a way that clients are always in contact with



Nieuw Unicum's buildings are surrounded by accessible terraces and gardens. Pictured from left to right, Thijs Möller, Mariska Bot, Herman Duiven and Yorick van der Vlugt are catching a few rays.

the same MS nurse consultants online, while a multidisciplinary team remains on standby.

This makes MS Remote Care a form of specialist care that is delivered at home and is both efficient and effective for all parties involved.

The MS Support Desk: bringing together questions and answers

Out of a shared responsibility to help people with MS, Nieuw Unicum and MS Vereniging Nederland have taken the initiative, with the support of Stichting MS Research, to develop and set up a telephone helpline, the MS Support Desk. The MS Support Desk offers a single and easily accessible point of contact for people with MS and their loved ones to obtain answers to all of their questions about living with MS. While there is a lot of information on the internet, people who suffer from a high-impact illness such as MS greatly appreciate the ability to contact a medical expert or expert patient personally and quickly. By contributing to the development and implementation



Neuromuscular electrical stimulation (NMES) is a form of therapy to address dysphagia.

of this service, Nieuw Unicum has once again demonstrated its commitment to supporting and helping people with MS.

Improving expertise

The aim of Nieuw Unicum's centre of expertise is to contribute to improving the expertise of colleagues at other institutions through knowledge sharing. A good example of this is Nieuw Unicum's accredited training programme for professionals, 'The multidisciplinary treatment of the consequences of MS'.

This is available to all physicians, nurses, neurologists, paramedics, psychologists and social workers who contribute to the quality of life of people with MS, but who don't have immediate access to Nieuw Unicum for reasons of distance. In the space of a single day, those professionals acquire knowledge about all MS-related domains, which allows them to optimise courses of treatment for their patients. Through knowledge sharing, Nieuw Unicum aims to boost expertise.

Specialist health care institution

In this way, Nieuw Unicum is developing itself from a stand-alone health care institution in the Haarlem region to a national MS platform, supplementing and cooperating with primary and secondary health care providers. ●



During the MS Training, professionals learn about useful methods to apply in everyday practice.

random **nieuw unicum**

Interested in visiting Nieuw Unicum's main site? You are always welcome for a tour without obligation. Contact Fred de Wit by emailing fdewit@nieuwunicum.nl or calling +31 (0)23 5761139.



Job Cohen, chair of the board of MS Nederland and member of the recommendations committee of Stichting MS Research, listens to an explanation of the FEES dysphagia test by Caroline Bruggeman, a speech therapist at Nieuw Unicum. Mr Cohen is closely involved with the latest developments regarding two disciplines that come together at Nieuw Unicum: MS research and MS treatment.

Expertise is a verb

Nieuw Unicum is fully aware that its status as a centre of expertise comes with both opportunities and responsibilities. New opportunities present themselves in the form of services for a growing group of people with MS – not just those at the most advanced stage, but particularly those at the stage just preceding it, who are otherwise unable to access Nieuw Unicum's specialist services due to the travel involved.

Nieuw Unicum shares its knowledge and expertise with health care providers throughout the country, so that specialist MS care is not the exclusive preserve of the people of Zandvoort. Last but not least, there are new responsibilities with regard to gathering and sharing knowledge and experience, both internally and independently as well as in partnership with research institutions and other organisations in the same field.

Partnership with VUmc's MS Center Amsterdam (MSCA)

Nieuw Unicum has built up a wealth of experience. It ranks highly on the learning curve, a measurement of best practices regarding the treatment and support of people with progressive MS and their loved ones, and in terms of the diagnosis of cognitive disorders caused by progressive MS. Both progressive MS research and cognition research

are key focus areas for the national and international research community, which is united in the Progressive MS Alliance. As a member of this alliance, the MSCA has gained extensive expertise with setting up and carrying out scientific research into cognitive disorders in people with MS.

It is therefore not surprising that Nieuw Unicum and the MSCA have decided to join forces with a view to a long-term partnership. This partnership was facilitated by a grant from Stichting MS Research. Among other things, the partners have now begun to map the so-called 'cognitive profiles' of people with progressive MS. The research team is being led by Professor Dr Jeroen Geurts. This project provides a solid foundation for follow-up research at a grander scale, but with the same objective of understanding and treating cognitive disorders in people with progressive MS. Evidently, Nieuw Unicum's unique clientele represents a 'hidden reserve' that scholars can tap into to further their research into MS and particularly the treatment of people with MS. Nieuw Unicum's clients, the MSCA's scientist and the institution's own treatment team form a powerful trinity. This valuable partnership also features research into the added value to the patient of a multidisciplinary approach and into the relation between dysphagia and MS. These research projects are led by the MSCA's Professor Dr Bernard Uitdehaag and Professor Dr Vincent de Groot.

Another investigation, which was initiated by Nieuw Unicum itself and has been running for some time, concerns the neuropsychological screening.

This screening can be considered a snapshot of a patient's cognitive condition. By subjecting people with MS to a neuropsychological screening as standard, a clearer picture emerges of their capabilities and limitations. Other

institutions, such as hospitals, are much less likely to carry out such a screening for MS patients, which can lead to late detection of cognitive problems. In fact, cognitive and mood problems are mainly invisible and are therefore at a much larger



Nieuw Unicum psychologist Dr Helga Harsay talks to client Josine Fonderie.



Physiotherapist Barbara van Marle with client Truus Borst.



VUmc's MS Center Amsterdam and Nieuw Unicum collaborate closely in the area of speech therapy research. Pictured from left to right are Dr Joke Geytenbeek, Professor Dr Vincent de Groot (both VUmc) and Leonie Ruhaak (Nieuw Unicum).

risk of being overlooked by both patients and professionals. At Nieuw Unicum, on the other hand, there is no delay. The right kind of attention leads to a solid foundation for targeted care.

People with MS often present with a complex and varied set of symptoms, including dysphagia. Nieuw Unicum's speech therapists not only strive to address and relieve the immediate symptoms of their clients or provide them with tips about other methods of communication, such as speech computers, but also carry out

research, particularly the kind of research that rapidly improves their clients' quality of life.

As an example, they are now working on a translation of the English-language Dysphagia in Multiple Sclerosis (DYMUS) questionnaire to improve existing diagnostics. This questionnaire can be used to confirm suspicions of dysphagia in people with MS. The outcomes of the questionnaire are compared with the result of the Flexible Endoscopic Evaluation of Swallowing (FEES) test. This test allows the

It is precisely cognitive and mood problems that are mainly invisible and are therefore often overlooked

therapist to map the swallowing process for different types of solids and liquids in great detail. Practical trials have revealed that the results of this test provide a great deal of information, which can be collated to arrive at a more tailored advice regarding the foodstuffs that should be ground or mashed. This type of advice could make all the difference in terms of quality of life. It is hoped that comparing and 'combining' the added value provided by both methods will eventually lead to even better advice for clients. Furthermore, it could prevent complications that can arise from dysphagia, such as pneumonia. The MSCA's Professor Dr Vincent de Groot is on hand to lend scientific support to this investigation as well. Together, the MSCA and Nieuw Unicum are investigating possible follow-up research in the field of communication and dysphagia in MS.

Nieuw Unicum is not only there to help people with MS, but also their carers.

This is exemplified by its short stay service, a service designed specifically for people with advanced-stage or progressive MS that allows them to spend a period of between one and eight weeks with Nieuw Unicum (on site). Years of experience have shown that this benefits both clients and their loved ones. The clients themselves undergo all desirable and necessary types of multidisciplinary screening, which often leads to simple yet highly useful advice. At the same time, their carers are able to relax and take a break from their duties. Clients take the results of the screening and the advice home with them, so that primary health care providers can use the screening results (separate and multidisciplinary) to optimise their care and treatment plans.

Nieuw Unicum sees the extent to which people with MS benefit from its unique

range of services each and every day. It would like to substantiate these positive experiences with objective findings by way of doctoral research, as a first step towards obtaining unbiased evidence for the added value of Nieuw Unicum's multidisciplinary approach. For instance, this could concern evidence that a short stay benefits the quality of life of both client and carer to such a degree that the client can live at home for longer.

Netherlands (MS) Brain Bank (NBB)

For the benefit of its research, Nieuw Unicum has also partnered with the Netherlands Brain Bank. The NBB was founded with the aim of finding causes and cures for neurological and psychiatric brain diseases. It works towards this aim ceaselessly by carrying out scientific research and lending brain tissue to research groups worldwide.



Thijs Möller receives a visit from Stichting MS Research ambassador Wolter Kroes. Thijs is staying at Nieuw Unicum long-term.

To this end, the NBB has built up an ever-growing collection of tissue, mainly belonging to people with MS.

Human dimension

When it comes to helping you become more than you already are, Nieuw Unicum is indubitably a national centre of MS expertise. It cares about people with MS, it cares for people with MS, it wants to be a dedicated research partner to the academic world and it strives for collaborative agreements with all professionals who treat and care for people with MS – without losing sight of the human dimension. ●

random **nieuw unicum**

Do you have any questions or do you want to find out more about Nieuw Unicum? Contact Fred de Wit by emailing fdewit@nieuwunicum.nl or calling +31 (0)23 5761139.



Many clients opt for a short stay before they move to Nieuw Unicum for a longer period, as did Rob van West, pictured talking to MS nursing consultant Joke Zwijnenburg.



Pass this magazine on or leave it in the waiting room for others to read