

## **Patients' Rights (Care Sector) Act: a summary**

A bill to strengthen the legal status of patients

### **Introduction**

Everyone who lives in the Netherlands is entitled to care. That right is enshrined in the Exceptional Medical Expenses Act (AWBZ) and other legislation and implemented through the broad basic health insurance provided for under the Healthcare Insurance Act. The government also carries out population screening and runs vaccination programmes. The municipal health services provide preventive care and join with other local providers to offer youth health care. All forms of care – preventive care, general medical care (including acute care) and long-term care – must be available and accessible to all. Patients must also be able to rely on continuity of care. Insurers have a duty of care, which means that, in general, the right to care is sufficiently guaranteed.

One of the aims of the proposed Patients' Rights (Care Sector) Act (WCZ) is to give patients the right to good care. Another is to give them a say in how care is provided and what form it should take. For this a solid legal basis needs to be established. To this end, the government set up a programme entitled 'Seven rights of the patient: investing in the patient-provider relationship' in 2008. The programme was devised in close consultation with patients, care providers and insurers and has been used as a basis for the WCZ bill, which still needs to be passed by the House of Representatives and the Senate before it becomes law.

The government hopes that the WCZ will strengthen and clarify the legal status of patients, both as individuals and collectively. The Act will entitle patients to good care, not just in terms of individual medical treatment, but in all relationships between patients and care providers throughout the care system. In future, patients will be better placed to opt for the care provider that suits them and their individual needs. The complaints system has also been simplified and made more effective.

The scope of the WCZ will extend beyond patients' rights and obligations to encompass the responsibility of care providers for the quality of care. By regulating the relationship between care provider and patient in a single statute, the rights and duties of both parties will be better attuned.

### **Patients are central**

The government seeks to establish a system of care that is good, safe, available when needed, accessible and affordable for all. In the Dutch system of care, patients are central. Care providers, care insurers and policymakers must design and tailor care from the perspective of patients. Besides having a practical effect on the relationship between care providers and patients, the WCZ represents a sea change in thinking on the management of care.

A relationship of trust between patient and care provider is essential to good care. On this footing, care providers can put all relevant questions to patients and go through the care options with them. Mutual trust means that patients must be able to count on receiving good care and on the care provider respecting their rights. For their part, patients must enable care providers to provide good care. Care providers must be able to count on patients cooperating with treatment, nursing and care. That means that patients are responsible for ensuring that care providers have all the information they need. They must also join with care providers in thinking and deciding about treatment options, and must follow the advice given by care providers as well as guidelines on lifestyle. The aim is to place the mutual relationship between patients and care providers on a clear footing by establishing general 'terms and conditions' that apply to both parties. This has already been achieved in the nursing, care and domiciliary care sector.

### **Why is a new Act necessary?**

At present, patients' rights and the attendant obligations of care providers are laid down in different Acts. This makes it difficult for patients to know exactly what their rights are, and for care providers to see how their obligations tie together. By merging the provisions from existing legislation into a single new Act, the legal status of patients and the functioning of care providers can be jointly regulated. Moreover, the creation of a single Act ties in with the aim of achieving greater coherence in care, for instance between primary and secondary care and between long-term and curative care. It also fosters transparency where all parties are concerned – an important means of enhancing the quality of care and increasing patients' influence.

Most of the rights set out in the programme 'Seven rights of the patient: investing in the patient-provider relationship' have been incorporated in the bill. In a number of cases the government has opted for an obligation on the part of the care provider rather than a right for patients.

### **To whom does the new Act apply?**

The WCZ applies to all procedures in the field of individual health care, including care in private clinics and 'care hotels'. The obligations it contains apply to care providers (for the purposes of the Act, the term 'care providers' covers the whole spectrum, from sole operators to organisations that either provide care themselves or arrange care for patients). The rights it contains apply to all (i.e. including decisionally incompetent patients) who apply to care providers for information, examination, advice, treatment, nursing or care. Care must be easily accessible to patients and must be sufficiently available.

The term 'patient' is used to refer not just to persons who are already receiving care, but also to those who are applying for care. This is relevant to the right to receive information to facilitate choice (see below), because this information is provided at a stage when a person is still looking for a care provider.

## **What rights and obligations are set out in the WCZ?**

### **Right to good care**

Under the terms of the WCZ, care providers are responsible for providing 'good care'. The term 'good care' was coined with two previous statutory definitions of care in mind: 'responsible care' from the Care Institutions (Quality) Act and the Individual Healthcare Professions Act, and 'care provided by a good caregiver' from the part of the Civil Code relating to medical treatment contracts (WGBO). 'Good care' is defined as care of a good standard that is, at the minimum, timely, safe, effective, efficient and patient-oriented. Care must be aligned to the patient's real needs and must accord with professional standards as laid down in guidelines. Good care entails a joined-up system, from early diagnosis of a condition to self-management and appropriate care. The WCZ accordingly obliges care providers to align and coordinate their efforts, both within and between organisations.

In order to meet its responsibilities, a care provider (represented by the management of the organisation) has to conclude a contract with those who are to provide the patient with care on the organisation's behalf (the health professionals). Such contracts stipulate that the health professionals in question (whether individuals or organisations) must comply with statutory obligations and adhere to the rules on care laid down by the care provider. Care providers must use quality monitoring systems to safeguard, control and improve the quality of care. Providers of alternative forms of care are incidentally not always bound by professional standards. However, care of this type may not harm or pose a serious risk to patients' health. The Healthcare Inspectorate can intervene if alternative care providers are suspected of malpractice.

Patients regard the right to quality and safety as the most important of the rights under discussion. Under the WCZ, providing safe care will become the explicit responsibility of the care provider. An important instrument in this context is an incident reporting system allowing staff to report incidents in their organisation confidentially with a view to preventing repeat incidents and enabling care providers to learn from any mistakes. The management of care institutions must instil in their staff the importance of quality, safety and openness.

### **Right to receive information to facilitate choice**

In order to be able to select the right care provider, patients must be well informed about the type of care on offer, its quality and its cost. With this information, patients can also compare the performance of care providers. At present, this is very hard to do, given the various different pieces of legislation involved. The WCZ gives patients the right to information needed for choice, amongst other things on the performance of the care provider, rates and other patients' experiences. Information of this type will soon be standardised, provided in an easy-to-compare format and made widely available. The right to such information exists independently of a care relationship, for it is precisely before such a relationship exists that patients need to make a well-informed choice.

Information of this type is not just relevant to patients. It can also for instance be used by family doctors wishing to refer patients. Care insurers and care administration offices can moreover use it in their policy on contracts.

### **Right to information, consent, file creation and privacy**

Care is only provided once a patient has given consent following an exchange of information with the care provider. Patients must have a clear picture of their state of health and treatment options, so that they can make responsible decisions and informed choices about health matters. The information supplied by care providers must be clear and formulated in a way that patients can understand. If treatment that may have a major impact on the patient is called for, the care provider must check whether the patient has understood the situation. This is important not only in hospitals and at doctors' surgeries, but also in the context of nursing, care and assistance. When the WCZ enters into force, the patients' rights laid down in the WGBO will therefore also apply to long-term care. Patients always retain the right to refuse consent or withdraw consent given on an earlier occasion.

Good care entails care providers keeping a record of discussions with patients and of their treatment. The WCZ accordingly gives patients the right to have their own file, with an

attendant obligation for the care provider to compile such a file. Files must be retained for 20 years, unless patients wish them to be destroyed earlier. These provisions have been taken, in a slightly amended form, from the WGBO.

The WGBO also regulates protection of privacy. This, too, has been incorporated in the WCZ. The protection of privacy includes a duty of confidentiality on the part of care providers and their staff as well as patients' right to privacy during the provision of care. These rights have been extended to apply to all care relationships, including long-term care. After all, privacy is a crucial element of the quality of life for patients living in care institutions.

### **The right to an effective, easily accessible complaints and disputes procedure**

When complaints are dealt with appropriately, patients feel confident that they are being listened to and taken seriously. Moreover, dealing with complaints provides information that can be used to improve the quality of care. Various studies show that patients find complaints procedures off-putting. They are not convinced that complaints are dealt with impartially and are often unhappy with the result. The WCZ prescribes a compulsory complaints and disputes procedure which offers better guarantees of independence and which is more transparent. Patients will also have access to free high-quality support, advice and information from a complaints officer or a confidential adviser.

The WCZ aims to ensure that complaints are dealt with where they arise, i.e. that they are resolved by the care provider. Patients whose complaints are not resolved in this way will have the right to present their case to an impartial, external committee. This is an accessible and quick way for patients to take action and receive a binding ruling. Patients' organisations will also be able to make use of this procedure. The WCZ will compel care providers to affiliate themselves with a disputes committee that issues recommendations that are binding on both parties. The parties will not be able to appeal against such rulings. They will be able to institute proceedings before a civil court, but a civil court will only assess whether the ruling was reasonable, it cannot rule on the merits of the case in the form of a judgment. Nevertheless, patients at all times retain the freedom to institute such proceedings if they are of the opinion that a care provider is breaking the law. If one of the parties does not adhere to the binding recommendations, a court can enforce compliance.

### **The right to participate in decision-making**

Decisions by care providers can have a far-reaching impact on patients' private lives. Patients must be given as much say as possible in decisions that affect their lives, ranging from the food they are offered to strategic decisions about residential care. This is why the

right to participate in decision-making on matters relating to care has been enshrined in law. The current Care Institutions (Patient Participation) Act (WMCZ) will be repealed and replaced by provisions in the WCZ.

The obligation to establish a system of participation does not apply to all care providers, only to those that provide intramural or extramural care falling under the Exceptional Medical Expenses Act, or other forms of intramural care. Care providers will have to draw up written rules on participation in decision-making and establish at least one patients' council. This last obligation does not, incidentally, apply to institutions providing GP services, paramedical services, dental services, obstetric services, maternity care or ambulance services, because these do not constitute intramural care. Suppliers of medical aids and nursing items, too, are exempt from the requirement to have a patients' council. The obligation applies only to care providers who, as a rule, employ more than 10 care staff.

Patients' councils must be able to advise on decisions that affect patients, for instance decisions relating to the quality of care, residential issues or mergers. The WCZ contains a list of subjects on which patients' councils must be consulted before decisions can be taken. In the case of decisions that affect patients' daily lives, the councils will have the right to give or withhold approval, analogous with the powers invested in works councils. Patients' councils will also have some influence on care providers' boards of management and supervisory boards. Under the terms of the WCZ, patients' councils will be entitled to issue a binding nomination for one of the members of the supervisory board.

The care provider must provide the patients' council with every resource that is reasonably necessary to carry out its tasks, including the use of facilities, a budget for regular activities and a budget for training. The most likely approach is that patients' councils will set out estimated expenditure in a work plan and a budget. Actors in the field have drawn up a model scheme establishing norms for funding patients' councils.

The final provision concerning participation is that care providers must be affiliated with a committee of confidential advisers set up by care providers' organisations and patients' organisations. This committee will give binding rulings, for instance on the budget for patients' councils.

### **Good management and supervision**

The WCZ invests patients with rights. Section 2 of the Act lays down matching obligations for care providers, requiring them to enable patients to enjoy those rights. Patients must be

able to rely on care providers making the quality and safety of care their first priority. They must also be able to call the care providers' management and supervisory boards to account on this head. All statutory obligations in the bill apply expressly to care providers – and thus their management boards – rather than to the professionals who actually provide the care. Yet this does not mean the latter can act with impunity: they have to be answerable to the management board, so that the latter can fulfil its responsibilities. If necessary, a management board can issue instructions to professionals or terminate their employment or accreditation contracts.

The government wishes to stress the importance of quality of care as a separate managerial issue. The WCZ accordingly provides that one of the members of the management board be given explicit responsibility for the quality portfolio, just as a particular board member is currently made responsible for the finance portfolio. This means that care insurers, patients and the Healthcare Inspectorate know exactly which member of the board to contact regarding quality issues.

To fulfil their new role, care providers need to have a professional supervisory body, for instance a supervisory board. Effective supervision of management will benefit the quality and safety of the care provided. The supervisory body must adopt a critical and independent stance, and must also take action if the management board takes unsound decisions. The WCZ will invest supervisory bodies with more extensive and enhanced statutory powers to monitor the management board effectively.

### **Reporting and social accountability**

In the new care system, care providers have been given greater freedom of operation and greater responsibility. As a result, they will have to account to all parties concerned on matters of policy and policy implementation. Care providers already have duties of accountability under a range of statutory provisions. In certain respects these will be expanded in the WCZ. For instance, private care institutions, whether they provide curative or long-term care, will be obliged to report not only on quality, but also on other relevant issues. Care providers who are sole operators will have to report on the quality of their care and their policy on quality.

With a view to reducing the administrative burden on care providers, the WCZ will introduce certain exemptions on reporting. Sole operators or care providers who employ fewer than 11 staff no longer need report on sound management, participation in decision-making or complaints.

In recent years there has been considerable focus on the social impact of activities carried out by corporations. To be socially accountable, a corporation has to provide transparency on its aims, results and working methods. Care providers bear the same responsibility. They must provide their patients with good care and supply transparent information on their activities. Under the provisions of the WCZ, care providers will be socially accountable as well as accountable for the expenditure of public funds.

### **How will the rights and obligations of patients and care providers be enforced?**

The WCZ endows patients with individual rights, and patients can enforce these rights. The first step in this process is to make use of care providers' internal complaints procedures. If that does not have the intended result, patients can present their case to an impartial, external committee and, if that proves unsatisfactory, they can apply to the civil courts. In principle it is up to patients to decide whether to take action, possibly with the support of third parties, in response to an infringement of their rights.

It would not be in keeping with the role of the Healthcare Inspectorate if patients were to ask it to respond to every single violation of an individual right. Yet the Inspectorate does have a supervisory task with regard to the WCZ, notably safeguarding the quality of health care and the interests of patients in a general sense. Supervision can focus on care providers' compliance with obligations, but also on the extent to which patients are enabled to enjoy their rights. The Inspectorate has a number of enforcement instruments at its disposal, varying from issuing written instructions to imposing an administrative fine or a penalty payment. In the most extreme case, the Inspectorate can order the provision of care to cease. The Inspectorate does not have to act as an enforcer in every case, but it will act if the safety of patients or of care might be jeopardised.

Other bodies besides the Health Inspectorate monitor care. The Dutch Healthcare Authority monitors compliance with the rules on transparency regarding the cost/quality ratio. An independent authority responsible for overseeing the closure or merger of care institutions, the CSZ, monitors the sale of real estate and the ban on profit-making care. The Data Protection Authority (CBP) monitors compliance with the rules on privacy. These bodies will draw up agreements with one another on how to deal with overlaps in supervision.

### **In sum: the main reforms in the Patients' Rights (Care Sector) Act**

The WCZ strengthens the position of patients in two ways. Firstly it gives them more rights. Secondly it creates more guarantees of good care.

**More rights for patients:**

- patients' rights will apply to all care relationships, including long-term care;
- patients will have the right to receive information to facilitate choice;
- patients will have the right to be informed of incidents;
- patients will be better placed to enforce their rights vis-à-vis care providers through an improved complaints procedure and an independent disputes committee;
- patients' councils will be given additional powers and better funding.

**More guarantees for good care:**

- one member of the management board of a care provider will be made responsible for the 'quality of care' portfolio;
- management boards will be given greater control with regard to the health professionals employed by their organisation (power to issue instructions and to terminate employment or accreditation contracts if staff do not perform their jobs properly);
- health professionals will be accountable to management boards;
- it will become easier to apply statutory requirements to the quality of care;
- the Healthcare Inspectorate will extend its scrutiny to compliance with patients' rights and will act if the safety of patients or care is seriously jeopardised;
- the Inspectorate can take action if the providers of alternative forms of treatment are suspected of malpractice.