

Inclusion Europe

The European Association of Societies of
Persons with Intellectual Disabilities and their Families



How to get easy to understand information about health care

Information and campaign kit for self-advocates

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This report was funded by the European Union. The EU bears no responsibility for the contents of the report.

2017 Inclusion Europe

1. Introduction

People with intellectual disabilities need better access to health care. They need health information in a language they can understand. Only with that information they can take good decisions about health. This information will also help a lot of other people. For example those who do not understand well the language of their country.

Disability organisations have written easy-to-read information since many years. Some hospitals and medical doctors already use this information. There are many examples of good practices. But they are often difficult to find.

Inclusion Europe wants to show which health information should be available.

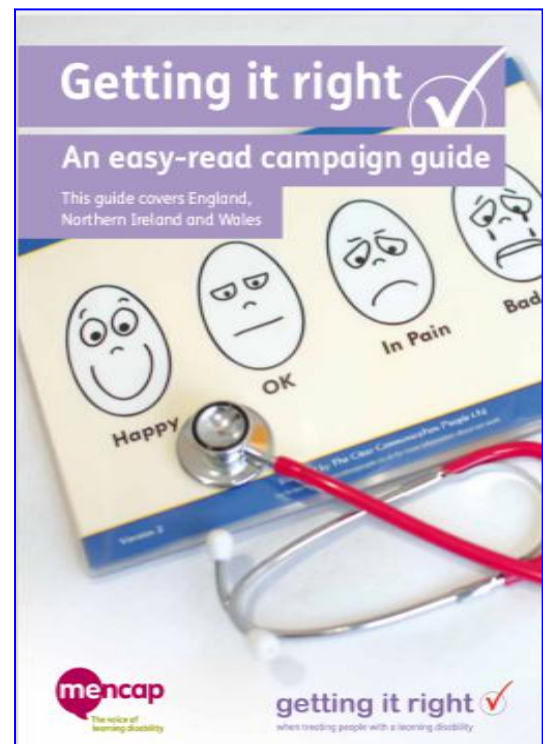
We want to show examples of understandable health information. We also want to explain the importance of good personal support.

Only with accessible information and good support can people with intellectual disabilities take good decisions about their health.

We want that everybody has the same chances to live a healthy life.

This paper will help advocates with intellectual disabilities to ask for the necessary support and information. It encourages people with intellectual disabilities to become actively involved.

This paper is written in plain language. Self-advocates and others will be able to use it for their work.



2. How should people with intellectual disability receive health information?

Receiving and understanding health information is difficult for many people, not only for people with intellectual disabilities.

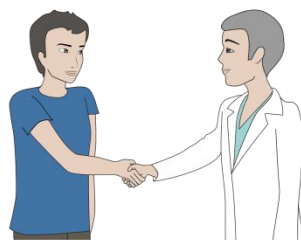
There are mainly 2 reasons for this:

- 1) The information itself is difficult to understand.
Medical doctors need to study many years to understand it.
- 2) Medical staff and doctors are often not prepared to explain it.
They are not trained to explain things in an easy way to other people.

Both problems are not easy to solve.

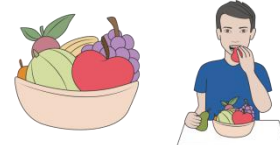
Some hospitals and organisations have written easy-to-understand texts or done videos to inform people with intellectual disabilities about different health issues.

This information helps people with intellectual disabilities to get basic information:



www.santebd.org image database

- **General advice on how to lead a healthy life,** for example what to eat, how to take care of yourself or about the importance of exercise.



www.santebd.org image database

- **Special information about different illnesses,** for example about a flu, what to do in case of stomach pain or if you have hurt yourself.

- **Information about treatments and medicines,** for example when and how to take your medication.

- **Information about how to use the health services,** for example going to the chemist, a doctor, the dentist or going to the hospital.



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This is the basic information that should be available to all people with intellectual disabilities in their language. We need to get better in ensuring that the existing information reaches the people who need it.

However, written information is not enough!

There are people who cannot read well enough. Most people will have personal questions about their health.

This is why personal support is very important!

Many people with intellectual disabilities get help from a family member or service staff.

This is fine if the supporter observes some basic rules:

- The supporter should have the necessary skills and materials to communicate with the patient.
- Doctors should not speak only to the supporter, but directly with the patient with an intellectual disability. The supporter only facilitates this communication.
- Decisions about treatments are taken only by the patient and not by the supporter.

If patients with intellectual disabilities are not sure about a treatment they have - like everybody else - some possibilities:

- They can go to another doctor and ask for a second opinion.
- They can ask friends and family members for advice.
- They can go to independent patients' organisations and ask for advice.

Some health services offer also special support:

For example the health services in Glasgow, Scotland, have a team of nurses who support the health care for all adults with intellectual disabilities.

The team works with doctors, hospitals and disability services.



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3. What are your rights to information?

In some cases it may be helpful to know that you have a right to accessible information.

Most people will not go to court to get their rightful information.

And there are big differences between international law and national law.

What is then done in practice is again another matter.

But it is often helpful to know your rights when talking to other people.

There is an international law about these rights.

It is the “Convention on the Rights of People with Disabilities”.

You can find an easy-to-read version here:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/345108/easy-read-un-convention.pdf

This law says that people with disabilities must get the same health services as all other people.

It also says that this must be

“on the basis of free and informed consent”.

This means that you have the right to

- 1) Get information in a form that you can understand.
- 2) Get the necessary support to understand this information.
- 3) Decide yourself if you want a treatment or not.
- 4) Tell the doctor a clear “yes” or “no” to the treatment.

The health services cannot do the treatment if you do not agree.

This applies to all medical treatments.

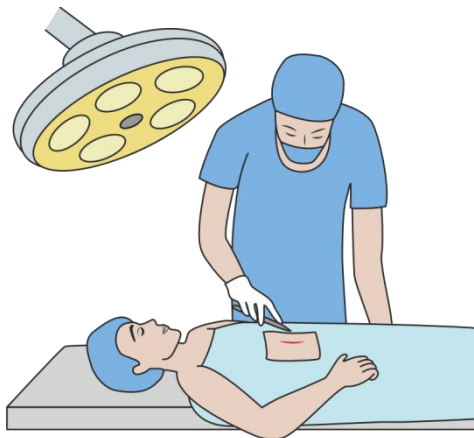
There are only exceptions in emergency situations, for example if someone has been run over by a car.



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In most situations this consent is not so important, for example when the doctor treats you for a flu.

But it becomes very important in case of bigger treatments, like:



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- medicine that changes your mind or thinking
- contraceptives, abortion, or sterilisation
- restraining your movements, for example by tying you to a bed
- putting you into a hospital without your agreement

You should know that all of this is not legal, if you do not agree.

The international law also says that doctors and nurses should be trained to know about these rights.

They should also be trained to give you this information.

4. What information should you get?

There are many different health problems and procedures. Of course, we cannot list here everything you should receive information about. But we have looked at the information that is already available in different countries. We believe that easy-to-understand information should be available at least on the following topics:

General advice on how to lead a healthy life

- Drinking
- Drugs and dependencies
- Exercise
- Food and diet
- Health at work
- Keeping clean
- Love and sex
- Menopause
- Old age
- Periods or menstruation
- Sexual health for men
- Sexual health for women
- Smoking
- Weight
- Wellbeing



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Special information about different illnesses and conditions

- Abuse
- Asthma
- Blood pressure
- Bowel and bladder
- Breathing problems
- Cancer (different forms)
- Constipation
- Diabetes
- Dying
- Ear problems
- Epilepsy
- Eye problems
- Falls
- Feeling upset
- Flu
- Grief
- Heart disease
- Mental health
- Pain and discomfort
- Sexually transmitted infections
- Teeth problems



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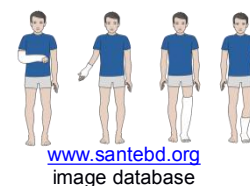
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Information about treatments and medicines

- Blood test
- CT scan
- EEG
- Endoscopy
- Hearing aids
- Information about medicines
- MRI scan
- Occupational therapy



- Palliative care
- Physiotherapy
- Postural care
- Precautions with medicines
- Vaccinations
- X-rays



Information about how to use the health services

- Confidentiality
- Consent
- Going to the chemist
- Going to the dentist
- Going to the doctor
- Going to the hospital



- Going to the optician
- Hospital passports or health books
- How to call an ambulance
- Insurances and payments
- Living will or advance statement
- Taking your medicine
- Talking to health professionals
- What to do in an emergency

Practical tools for doctors and nurses

To improve the accessibility of health services, we find also practical tools for doctors and nurses very helpful. These should also be available in one place for each country or language.

For example, the French site www.santebd.org offers health images to download.

These can help doctors and hospitals to make their documents more accessible.

Most of the images in this paper are from santebd.



Another good example for a practical tool are Tip Cards from Scotland. They are for ambulance staff, dentists, doctors and all others who have direct patient contact. The cards are a quick reminder.

You can find them at: <http://www.healthscotland.com/uploads/documents/5809-Updated%20Tip%20Cards%20-%2031.01.08.pdf>



Another useful tool we found on the website of the health services in Lanarkshire, United Kingdom. Here they provide draft letters for doctors and health services in easy-to-understand language. You can find the examples here:

<http://www.healthlanarkshire.co.uk/letter-templates>



Training packs for self-advocates

We also should make sure that everybody is well trained. For this, training packs for self-advocates are very helpful.

You can find one example at <https://www.sclld.org.uk/healthy-eating-healthy-living-pack/>

We did not find an example training for doctors and nurses about intellectual disabilities.

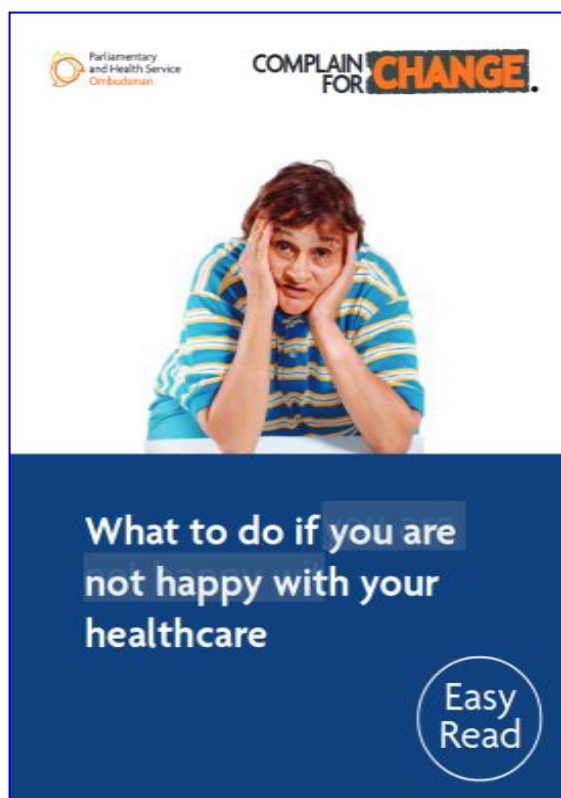
If you know about one, let us know!

How to complain if things go wrong

In all European countries you can complain about your doctor or your hospital. There are different patient's organisations or government agencies who take your complaint. You have the right to get information about where to go when you want to complain.

Here you can find an example from the United Kingdom:

https://www.mencap.org.uk/sites/default/files/2016-06/EASY_READ_Tips_on_making_a_complaint_NHS.pdf

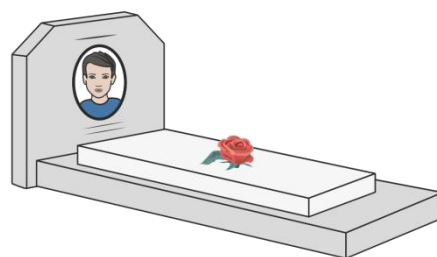


Finally, we have to talk about when it all goes wrong. Many people with intellectual disabilities actually die because they do not get the right treatment. But disability organisations and researchers do not get to know about this. Health information is confidential and doctors cannot give it to other people.

That is why we find it important that disability organisations set up a system where people can inform them about deaths because of bad treatment. This can help a lot to make health services better. You can find an example at:

<https://www.bris.ac.uk/sps/leder/notification-system/>

But this is unfortunately not accessible for people with intellectual disabilities themselves.



www.santebd.org image database

5. Finding information in your language: what you should campaign for

All this information may exist already in your language.
You may need help to find it on the Internet.

The first step you can do is to check if the information is there in your language.

- If it is there, you can check if it is really accessible.
You can also ask a medical person to help you checking if all the information is correct.
- In many countries the information may not be there in easy-to-read language.
Then you should do a campaign to get it.
You can ask a medical person to support you with this.
You can ask your government for support.



If you need to start writing new information about some things, you will need to make sure that what you write is correct.
A medical person can help you checking this.

At www.easy-to-read.eu you can find guidelines on how to write in easy language in many European languages.



You can also start with existing information from other languages.
If you get it translated, you have a good starting point.
But you should always work on the text to make sure it works in your country.

We have seen that in many countries some information is already there in easy-to-read language.
But it is often not complete.
And it is often not easy to find.
It would be great to collect it all in one place.

We have found 3 good examples for this:

The French organisation www.santebd.org

has created a website with accessible information in all areas of health.

It is led by a working group of 40 representatives of different types of disability and health professionals.

A group of experts is in charge of the illustrations.

We like here that this is supported by many mainstream organisations.

We like also that it is not only for people with disabilities.

It works like this:

1. You select what you want to know about.
2. You select if you are a boy, a girl, a man or a woman.
3. You select the kind of difficulties you have.
4. At the end you can open an easy-to-understand text.



Inclusion Czech Republic has done the site <http://www.ozdravi.org>

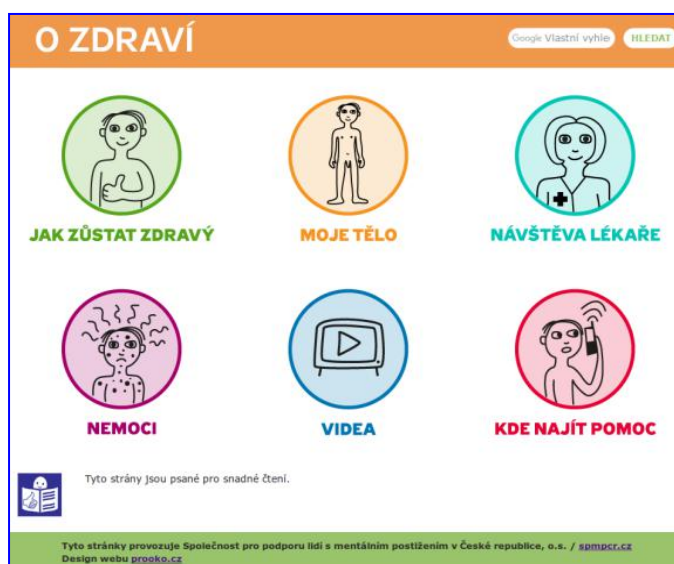
”O zdraví” means “about health” in Czech language.

Here the Czech Ministry of Health has given the money.

The site was developed together by self-advocates and medical doctors.

You can find also videos and a helpline.

The site has all one design and is very often used.



Easyhealth is a very good example in English language.

You can find it at www.easyhealth.org.uk

Easyhealth found that there is already a lot of accessible information about health in English language.

Their goal is to collect all this from many different people and make it available for everybody. Easyhealth was made so that people know where to find accessible health information. There are over 500 leaflets, made by many different organisations. You can print off nearly all the leaflets straight away.

The information has many different styles and forms.

There may be also several leaflets about 1 health question.

This can be confusing,

but it is also a great source of inspiration for your own work.



Regardless of which model you choose to make health information accessible in your country

WE WISH YOU MUCH STRENGTH AND SUCCESS

And if you have any success or good practice to report, Inclusion Europe will be happy to hear about it.

6. Available information

We have looked on the internet for good health information in accessible language.

There is a lot of information available in some languages.

In other languages there is almost no accessible information.

Below, we are sharing this information with you.

Some people may be interested also in information in other languages.

... in English

- FAIR (Family Advice and Information Resource) is an information and advice service for people with learning disabilities and carers in Edinburgh. Excellent Information is available against payment <http://www.fairadvice.org.uk>
- NHS Lanarkshire Adult Learning Disability Service developed this site so that people with a learning disability can get accessible health information in various formats. The website has leaflets & booklets, DVD's and easy read letter templates which aid health professionals to communicate effectively with their patients. <http://www.healthlanarkshire.co.uk/>
- The Learning Disabilities Mortality Review (LeDeR) Programme supports local areas to review the deaths of people with learning disabilities. <https://www.bris.ac.uk/sps/leder/notification-system/>
- The Easyhealth website is a fantastic resource for anyone looking to access clear, practical and easy to understand health information. There are over 500 leaflets on Easyhealth, made by many different organisations. You can print off nearly all the leaflets straight away: <http://www.easyhealth.org.uk/>
- Hospital passport: <http://www.nhs.uk/Livewell/Childrenwithalearning%20disability/Documents/Hospital%20Passport%20Template%20example%20from%20South%20West%20London%20Access%20to%20Acute%20Group.doc>

- Health book: <https://www.downs-syndrome.org.uk/?wpdmdl=1289&ind=0>
- How to complain for change: https://www.mencap.org.uk/sites/default/files/2016-06/EASY_READ_Tips_on_making_a_complaint_NHS.pdf
- Stay well this winter: https://www.mencap.org.uk/sites/default/files/2017-11/SWTW2017_EasyReadLeaflet_WebAccessible.pdf
- All about the flu and how to stop getting it: <https://campaignresources.phe.gov.uk/resources/campaigns/34-stay-well-this-winter-/resources/2345>
- The Tip Cards were made for ambulance staff, dentists, general practitioners and all others who have direct patient contact. The cards are intended as a quick reference guide:
<http://www.healthscotland.com/uploads/documents/5809-Updated%20Tip%20Cards%20-%2031.01.08.pdf>
- Health information for supporters and staff members:
http://www.turning-point.co.uk/media/1100930/tp-health-toolkit-2016_web_.pdf
- The ‘Healthy Eating, Healthy Living’ training pack is designed to encourage healthy eating as a way of life for people with learning disabilities: <https://www.sclد.org.uk/healthy-eating-healthy-living-pack/>
- Cancer: <https://www.mariecurie.org.uk/help/publications/easy-read-booklets>
- A Participatory Action Research Project into the Implementation and Evaluation of My Healthcare Passport:
<https://www.fons.org/library/report-details?nstd=71699>

... in other languages

Deutsch

- Liebe, Sex und Zärtlichkeit: http://www.chancen-erarbeiten.de/fileadmin/webdata/PDFs/Inhalte_Liebe.pdf
- Sucht und Drogen: http://www.chancen-erarbeiten.de/fileadmin/webdata/PDFs/Inhalte_Sucht.pdf

- Gesund essen Tag für Tag: <https://www.lebenshilfe.de/wData/downloads/leichte-sprache/freizeit/Erna--hrung-LS.pdf>
- Infos zum Thema Lungen-Krebs: <https://www.lebenshilfe.de/de/leichte-sprache/freizeit/Gesundheit/Lungenkrebs.php?listLink=1>
- Kiffen und Rauchen sind riskant: <https://www.lebenshilfe.de/de/leichte-sprache/freizeit/Gesundheit/Alkoholindex-Kopie.php?listLink=1>
- Patienten-Verfügung in Leichter Sprache: <https://www.lebenshilfe.de/de/leichte-sprache/freizeit/Gesundheit/Patientenverfuegung.php?listLink=1>
- Menschen mit Behinderung im Krankenhaus: <https://www.lebenshilfe.de/de/leichte-sprache/freizeit/Gesundheit/MmB-im-Krankenhaus.php?listLink=1>
- Alkohol ist gefährlich: <https://www.lebenshilfe.de/de/leichte-sprache/freizeit/Gesundheit/Alkoholindex.php?listLink=1>
- Süchtig sein kann man von vielen Dingen: Alkohol, Zigaretten, Essen, Computer und vielem mehr. Eine Sucht-Selbsthilfe-Gruppe in Berlin: <https://www.lebenshilfe.de/de/leichte-sprache/freizeit/Gesundheit/SeSuGrup-Berlin.php?listLink=1>
- Was kann ich für meine Gesundheit tun? <https://www.lebenshilfe.de/de/leichte-sprache/freizeit/Gesundheit/gesundheit.php?listLink=1>
- Impfen ist wichtig für die Gesundheits-Vorsorge. Auf seine Gesundheit sollte man immer gut aufpassen. Denn die eigene Gesundheit ist sehr wichtig. Impfungen können vor vielen Krankheiten schützen. Hier bekommen Sie viele Informationen über Impfungen: https://www.stmgp.bayern.de/?lang=de_ls
- Die Gesundheit im Berufs-Leben - in Leichter Sprache: https://www.stmgp.bayern.de/leichte-sprache-uebersichtsseite/die-gesundheit-im-berufs-leben/?lang=de_ls
- Leichte Sprache und Gesundheit — Patiententelefon Webguide <https://www.patiententelefon.de/behinderung/allgemein-unterstuetzung/leichte-einfache-sprache/gesundheits-leichte-sprache>
- Leichter lernen mit dem Projekt GESUND! Für Werkstätten für Menschen mit Behinderungen: <https://www.vdek.com/content/vdeksite/vertre>

[agspartner/Praevention/projektgesund/_jcr_content/par/publicationelement_37/file.res/Broschuere-Projekt-Gesund.pdf](https://www.agspartner/Praevention/projektgesund/_jcr_content/par/publicationelement_37/file.res/Broschuere-Projekt-Gesund.pdf)

- Leichte Sprache Regeln für die Gesundheit und für die Pflege: <https://www.bar-frankfurt.de/fileadmin/dateiliste/publikationen/wegweiser/downloads/WWLeichteSpracheHeft3.web.pdf>
- Leichte Sprache - rauchfrei für Erwachsene - Rauchfrei-Info: <https://www.rauchfrei-info.de/informieren/leichte-sprache/>

Español

- 10 pequeños cambios para mejorar tu salud: http://www.plenainclusion.org/sites/default/files/43._10_pequenos_cambios_para_cuidar_tu_salud.pdf
- Guía de Salud para personas con discapacidad intelectual: http://www.plenainclusion.org/sites/default/files/36._personas_salud.pdf
- Cuando estoy enfermo escúchame: http://www.plenainclusion.org/sites/default/files/36._guia_escuchame.pdf
- Guía de utilización de antipsicóticos: http://www.plenainclusion.org/sites/default/files/38._antipsicoticos_secuencialectura.pdf

Français

- Toutes les fiches Santé BD ont été rassemblées dans une application qui permet une plus grande efficacité en termes de personnalisation, maintien de l'attention et mise à jour. <http://santebd.org/fiches>
- Brochure "Arrêter de fumer": <http://inpes.santepubliquefrance.fr/CFES/Bases/catalogue/pdf/1650.pdf>

Nederlands

- Steffie.nl-zowerkthet: Ik ben Steffie en ik leg moeilijke dingen op een makkelijke manier uit. Bijvoorbeeld reizen met de OV-chipkaart, hoe je gezonde keuzes maakt en wat het ondersteuningsplan is.
<https://www.steffie.nl/>
<https://www.steffie.nl/eenvoudige-websites/gezondheid/>
- Naar je huisarts: Op deze website leg ik uit hoe een afspraak bij de huisarts gaat en ik help je om je goed voor te bereiden. Je kan ook oefenen met het maken van een afspraak. <https://www.naarjehuisarts.nl/>
- Uitleg Zorgverzekering: Op deze website leg ik alles uit over de basisverzekering. Ik leg uit wat een eigen risico en een eigen bijdrage zijn en wanneer je zorgtoeslag kan krijgen. Zo leer je waar je op moet letten bij jouw zorgverzekering en welke zorgkosten door jou of door de zorgverzekeraar worden betaald. <https://www.uitlegzorgverzekering.nl/nl/>
- Kijk op gezond: Wil jij gezonder leven? Kijk hier hoe je gezonde keuzes kan maken en hoe je meer kunt bewegen. <http://www.kijkopgezond.nl>
- Bekijk het nuchter: Steffie legt op een eenvoudige manier uit wat alcohol en drugs met je kunnen doen. Doe ook de test! <http://www.bekijkhetnuchter.nl>
- Diabetes zelf in de hand: Hier vind je informatie over omgaan met diabetes. Voor jezelf of voor degene voor wie je zorgt.
<http://www.diabeteszelfindehand.nl/>