


Appendix 2

I. Welcome Page

The home page welcomes the surrogate decision maker to the website and gives an overview of the sections.

A “start here” tag is added to the first section to encourage the surrogate to view the website in order.



**Understanding
stroke**
A Guide
for Family
Decision Makers

Welcome to
Understanding Stroke:
A Guide for Family Decision Makers

Dealing with the aftermath of a stroke can be overwhelming -- not just for the patient, but also for their family. This website was designed to help guide you through this difficult time.

You can get started by choosing any topic below, but we suggest you go through them in order.

Start Here ▶ [About Stroke](#) covers types of stroke and common problems from stroke.

▶ [Stroke Outcomes](#) explains what happens when you have a stroke and includes a chart that may help predict your loved one's outcome.

▶ [In the Hospital](#) explains common types of treatment after a stroke.

▶ [Making Decisions](#) helps you think about what your loved one would want and includes an activity about their preferences.

▶ [After the Hospital](#) explains rehabilitation options and adjusting to life after stroke.

▶ [Asking Questions](#) has tips for talking with the health care team and includes space to keep track of your questions.

When you're finished, you can get a printout of your customized Summary Report and use it when you talk to the health care team.

Please click on a topic above to get started.

II. About Stroke

a. Types of stroke

The website starts by introducing the type of stroke the patient experienced.

Depending on what type of the stroke the patient experienced, the surrogate will see one of the two versions of content shown to the right.

Example for Ischemic Stroke (IS)

The screenshot shows the 'Understanding Stroke' website. The navigation bar includes 'About Stroke', 'Stroke Outcomes', 'In the Hospital', 'Making Decisions', 'After the Hospital', 'Asking Questions', and 'Summary Report'. The main content area is titled 'About stroke' and has a sub-header 'Topics on this page:' with links for 'Types of stroke' and 'Common problems from stroke'. The 'Types of stroke' section is highlighted. It defines a stroke as a brain attack where blood supply is cut off. It lists two main types: ischemic stroke and intracerebral hemorrhage. The ischemic stroke section includes a diagram showing a blood clot blocking an artery and a list of characteristics: most common (87%), caused by a blood clot, and lack of blood flow causes injury.

Types of stroke

A stroke (sometimes called a brain attack) is when the blood supply to part of the brain gets cut off. This can injure the brain and cause problems with movement, walking, talking, or other functions.

There are 2 main kinds of stroke: ischemic stroke and intracerebral hemorrhage. Your loved one had an ischemic stroke.

Ischemic stroke

INTRACEREBRAL HEMORRHAGE

- Most common type of stroke (about 87% of all strokes are ischemic strokes)
- Caused by a blood clot in an artery that blocks the flow of blood to the brain
- Lack of blood flow and oxygen to a part of the brain can cause that part to become injured

Example for Intracerebral Hemorrhage (ICH)

The screenshot shows the 'Understanding Stroke' website. The navigation bar is the same as above. The 'Types of stroke' section is highlighted. It defines a stroke as a brain attack where blood supply is cut off. It lists two main types: ischemic stroke and intracerebral hemorrhage. The intracerebral hemorrhage section includes a diagram showing a broken blood vessel leaking blood and a list of characteristics: also known as a 'brain bleed', less common (10%), occurs when a blood vessel breaks, and pressure from the blood can injure other parts of the brain.

There are 2 main kinds of stroke: ischemic stroke and intracerebral hemorrhage. Your loved one had an intracerebral hemorrhage.

Intracerebral hemorrhage (ICH) or hemorrhagic stroke

INTRACEREBRAL HEMORRHAGE

- Also known as a "brain bleed"
- Less common type of stroke (about 10% of all strokes)
- Occurs when a blood vessel breaks, causing blood to leak into the brain
- Pressure from this blood can injure other parts of the brain

b. Common problems from stroke

Common symptoms that patients may experience after a stroke is listed here as well. This content is the same for IS and ICH.

Common problems from stroke

Strokes affect people differently, depending on:

- How severe the stroke was
- The part(s) of the brain affected
- The person's age and general health

While each stroke is unique, some common problems that may occur include:

- Weakness or paralysis (inability to move)
 - Happens on the opposite side of the body from where the stroke was
 - May affect the entire side or just the face or arm or leg
- Problems with walking, balance, or coordination
- Problems with communication
 - Aphasia (a-FAY-zha) – difficulty speaking, reading, writing, or understanding others
 - Dysarthria (dis-AR-three-a) – muscle weakness that makes it difficult to speak clearly
- Not being aware of things on one side of the body
- Pain, numbness, burning or tingling feelings
- Partial loss of vision
- Problems with memory, thinking, attention, or learning
- Not being aware of limitations caused by the stroke
- Dysphagia (dis-FAY-ja) - trouble swallowing
- Problems with bowel or bladder control
- Getting tired very easily
- Mood swings
- Depression

Welcome

Stroke Outcomes

III. Stroke Outcomes

a. Levels of disability after stroke

A plain language description of each level of the modified Rankin Scale was created to accompany the prognostic information to help with interpretation of the prognostic model. Due to the study targeting a moderate to severe stroke population, and to minimize the number of displayed categories, mRS scores of 0-2 were combined to become a single category of “mild disability or better”. The other scores were maintained as distinct categories – “moderate disability”, “moderately severe disability”, and “severe disability”, for mRS 3, 4, and 5, respectively. Examples of residual symptoms were listed to help family members understand the range of possible outcomes. The descriptions also included examples on the types of assistance they may need, e.g., not able to live alone, need help with daily activities, etc.

What happens when you have a stroke?

Topics on this page:

- [Levels of disability after stroke](#)
- [Predicting your loved one's outcome](#)
- [Overview of the recovery process](#)

Levels of disability after stroke

People can have varying degrees of difficulty with daily activities after a stroke. Sometimes, the effects of the stroke are so severe that a person can die as a result.

The table below shows a range of possible difficulties that someone can have after a stroke. These categories are general descriptions, and people can move from one category to another as they recover.

- Your doctors can help describe the types of problems your loved one may have in the future. They can also explain how the stroke may affect your loved one's ability to get back to what they did before (e.g. work or other important activities).
- Note that it is common to have fatigue or mood changes after a stroke, even for people with otherwise mild symptoms.

SCALE	DESCRIPTION
Mild disability or better	<ul style="list-style-type: none">May have some mild symptoms of stroke, such as<ul style="list-style-type: none">– weakness– numbness– changes in thinking or speakingAble to live on their own and manage daily activities (bathing, shopping, preparing or getting meals and managing finances)
Moderate disability	<ul style="list-style-type: none">Not able to do all of the activities they could do before the strokeMay have difficulty thinking or speakingMay need help with some daily activities (bathing, shopping, preparing or getting meals, managing finances)Able to walk without help from another person, but may need a cane or a walker
Moderately severe disability	<ul style="list-style-type: none">Need help with some daily activities (eating, bathing, dressing, toileting)May have more severe difficulty thinking or speakingNot able to walk without help from another personMay need a wheelchairNot able to live alone
Severe disability	<ul style="list-style-type: none">Need help with most or all activities (eating, bathing, walking)Not able to sit up in bed without helpNot able to move from a bed to a chair without helpDo not have full control of bladder or bowel functionNot able to live aloneNeed constant nursing care and usually live in a long-term nursing facility

b. Predicting your loved one's outcome

A brief introduction is given on the prognostic calculator, including what it is and how it works. Some surrogate decision makers in our focus groups expressed the desire for the model to show outcomes beyond 3 months. However, due to limitations of the source data, we were unable to accommodate this request. To clarify to the audience that continued improvement is possible beyond 3 months, a sentence was added to explain this. (See first red arrow)

Participants in our focus groups also suggested that some people may find numeric prognoses distressing rather than helpful. Therefore, a preface was added to warn surrogates about the potential emotional distress and give the option to not view the personalized numeric prognosis. (see second red arrow)

Predicting your loved one's outcome

Doctors can't always predict exactly how a person will do after having a stroke. Recovery depends on many things: how severe the stroke was, which part(s) of the brain are affected, and other aspects of the person's health.

Stroke experts at the University of Michigan have created a calculator to help you understand more about your loved one's outcome. The calculator shows how similar patients have done at about 3 months after their stroke. While people can continue to improve for a year or more after a stroke, doctors have found that most recovery happens in the first 3 to 6 months.

How does the calculator work?

1. Information about your loved one and their stroke is entered into the calculator
2. Your loved one's information is compared to the records of more than 9,000 people with stroke, including:
 - Type of stroke: ischemic or intracerebral hemorrhage (ICH)
 - Severity of stroke
 - Age
 - Gender
 - History of diabetes or atrial fibrillation
 - Whether they received a clot busting medication such as tPA (ischemic stroke only)
3. Based on how similar patients did after their stroke, the calculator shows the likelihood of your loved one falling into one of 5 categories at 3 months:
 - Mild disability or better
 - Moderate disability
 - Moderately severe disability
 - Severe disability
 - Death

What else should I know about the calculator?

The calculator was developed to help show how much recovery a person may have after their stroke. The results are based on the experience of other people with similar strokes.

The calculator is not a perfect tool. It cannot predict exactly how your loved one will do. We encourage you to talk to your doctor about your loved one's outcome, especially if they had a procedure to remove the blood clot (thrombectomy).

- **Some people may find it helpful** to see the calculator so they can have a better sense of what the future might be like for their loved one.
- **Other people may not find it helpful**, because it is only an estimate and cannot tell you how your loved one will do. They may also find it upsetting to see, since it may include the possibility of a person dying as a result of the stroke.

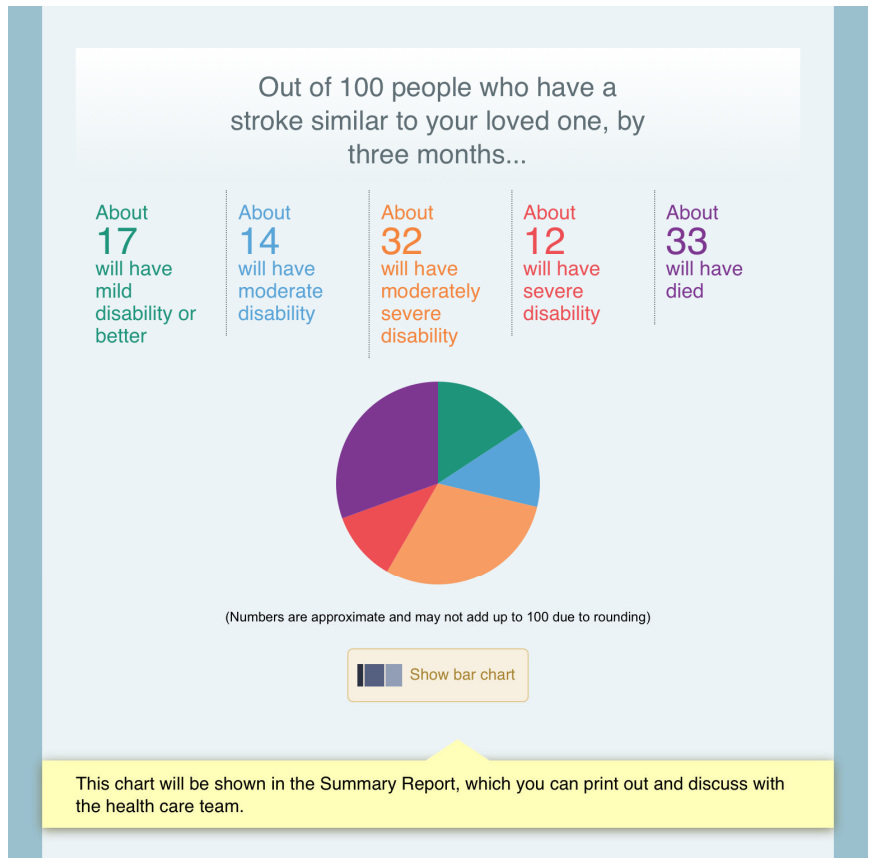
Would you like to see the results for your loved one?

Yes

No

c. Graphical presentation of prognosis

We included the option to toggle between a pie chart, which was overwhelmingly favored by patients, surrogates, and providers alike, and a horizontal stacked bar chart, which is commonly shown when reporting stroke clinical trial results.



d. Overview of the recovery process

A brief overview is given on the recovery process.

Overview of the recovery process

Recovering after a stroke is different for everyone. Some things that affect recovery are:

- How severe the stroke was
- The part(s) of the brain affected
- The person's age and general health

Recovery begins as soon as possible after the stroke and continues for months, or even years. These are the steps in the recovery process:

- **Hospital (acute) care** – Recovery starts with treatment at the hospital to help the patient survive and address the medical reasons for the stroke.
- **Spontaneous recovery** – Many people will naturally start to recover some of their abilities in the first few weeks after a stroke. This may also continue over a long period of time.
- **Rehabilitation** – “Rehab” often begins in the hospital to encourage movement and start the healing process as soon as possible.
 - Depending on how a patient is doing, rehab may continue in a nursing home, rehab center, or at home.
 - The first few weeks are the most intensive, and most improvements are seen within the first 3 to 6 months.
 - For some, recovery may take a year or longer, and some may continue to improve over many years (but this is not usually the case).

About Stroke

In the Hospital

IV. In the Hospital

a. Very early treatments

Early treatments for intracerebral hemorrhage (ICH) or ischemic stroke (IS) are listed on this page (tailored to patient condition). This helps the surrogate decision maker understand what decisions they may be asked to make on the patients' behalf.

Intracerebral Hemorrhage

The screenshot shows the 'Understanding Stroke' website. The top navigation bar includes 'About Stroke', 'Stroke Outcomes', 'In the Hospital' (selected), 'Making Decisions', 'After the Hospital', 'Asking Questions', and 'Summary Report'. The main content area is titled 'In the hospital' and has a sub-header 'Topics on this page:' with links for 'Very early treatments' and 'Other medical treatments after stroke'. The text states: 'Treatment for a stroke depends on several factors, including:'. A bulleted list follows: 'The type of stroke', 'How much time has passed since the stroke happened', and 'The functions or abilities that have been affected by the stroke'. A section titled 'Very early treatments' explains that an intracerebral hemorrhage (ICH) occurs when a blood vessel breaks and bleeds into the brain. It notes that treatment focuses on controlling bleeding and reducing pressure. A bulleted list includes: 'The bleeding puts pressure on other parts of the brain', 'The bleeding is in an area that surgeons can safely reach', and 'The damage is not already too severe'. It then lists 'There are several types of surgery for ICH:'. Three types are detailed: 'Craniotomy' (removing a piece of the skull), 'Craniectomy' (removing a section of the skull due to swelling), and 'Ventriculostomy' (a tube to drain fluid and measure pressure).

Ischemic Stroke

The screenshot shows the 'Understanding Stroke' website page titled 'Very early treatments'. The text states: 'There are some very early treatments for ischemic stroke, but not all patients are eligible to receive them. It depends on:'. A bulleted list includes: 'How much time has passed since the stroke happened', 'How severe the stroke was', 'The location of the blood clot', and 'Other medical factors'. It then explains: 'In an ischemic stroke, a blood clot blocks the flow of blood to the brain. The goal of treatment is to break up or remove the clot within the first few hours of the stroke.' A section titled 'There are several types of treatment for ischemic stroke:' lists three types: 'Tissue Plasminogen Activator (tPA)' (a 'clot buster' given via IV within 3-4.5 hours), 'Mechanical Thrombectomy' (removing a clot through a catheter in the groin), and 'Craniectomy' (removing a section of the skull due to swelling).

b. Other medical treatments after stroke

Other common medical treatments or key decisions (i.e., DNR orders) for ICH and IS patients are briefly introduced here as well.

Each treatment is organized into an accordion that can be expanded or closed depending on surrogate interest.

Other medical treatments after stroke

These are some common treatments that are used to help a patient survive after a stroke. You may be asked to help decide whether or not your loved one should receive these treatments.

Tap or click on a treatment below to learn more

- + **Cardiopulmonary Resuscitation (CPR)**
- + **Breathing Machine (Ventilator)**
- + **Tracheostomy**
- + **Feeding Tube**

Stroke Outcomes Making Decisions

- **Cardiopulmonary Resuscitation (CPR)**

- CPR is an emergency procedure for a person who is not breathing or whose heart has stopped.
- It involves chest compressions (pressing on the chest) and may also include defibrillation (electric shock to restart the heart).
- A note about DNR:
 - Some patients may have a **DNR (Do Not Resuscitate)** order. This means they do not want to have cardiopulmonary resuscitation (CPR) if their heart stops or they stop breathing.
 - DNR is the most commonly used term, but you may also hear Do Not Attempt Resuscitation (**DNAR**) or Allow Natural Death (**AND**).

- **Breathing Machine (Ventilator)**

- A tube is placed down the throat and a machine moves air in and out of the lungs to help a patient who can't breathe well on their own.
- This is often only needed for a few days after a stroke. Sometimes people may need help supporting their breathing for a few weeks or more (see "Tracheostomy" below).

- **Tracheostomy**

- A tracheostomy (tray-key-OS-tomy) is a small surgical opening is made in the neck. It allows a tube to go into the trachea (windpipe) to help a patient breathe.
- This is placed when people are expected to need help with breathing for more than a few weeks.
- It also makes it easier for nurses to suction out extra saliva that can make it hard to breathe.

- **Feeding Tube**

Short-term

- A small flexible tube is passed into the stomach from the nose. Doctors commonly refer to this as an NG (nasogastric) or Dobhoff Tube.
- It is used for giving medication or nutrition when swallowing is a problem.
- It is usually only used for about 1-2 weeks. People with swallowing problems that last longer may need a long-term feeding tube (see below).

Long-term

- A tube is placed in the abdomen to supply medication or nutrition to the stomach.
- It is used when people are expected to have swallowing problems for more than a few weeks.
- It can be removed if swallowing improves after a few months.
- Some people need it for the rest of their life because they never get back their swallowing ability after a stroke.
- People with a feeding tube can be in a rehabilitation or nursing facility or at home. It depends on the other problems that they are having from the stroke.

Stroke Outcomes Making Decisions

V. Making Decisions

a. Making healthcare decisions for someone else

This section describes what it means to be a surrogate decision maker and how to make healthcare decisions for someone else.

The screenshot shows the 'Understanding Stroke' website. The top navigation bar includes links for 'About Stroke', 'Stroke Outcomes', 'In the Hospital', 'Making Decisions' (highlighted), 'After the Hospital', 'Asking Questions', and 'Summary Report'. There are also icons for font size, resources, about, and log out. The main heading is 'How can I decide what's best for my loved one?'. Below it, a 'Topics on this page:' box lists three links: 'Making healthcare decisions for someone else', 'Thinking about the goals of your loved one's treatment', and 'Thinking about what your loved one would want'. A dark grey box highlights the section title 'Making healthcare decisions for someone else'. The text explains that making healthcare decisions for another person can be difficult and stressful, and lists three reasons: needing to make decisions quickly, feeling pressure from others, and not having all the information. It then defines a surrogate decision maker and mentions the 'Durable Power of Attorney'. The section concludes with three numbered questions: 'What have they said in the past?', 'What would they want?', and 'What do I think is in their best interest?'. Each question is followed by a paragraph of advice.

Understanding Stroke

Font Size Resources About Log out

About Stroke Stroke Outcomes In the Hospital Making Decisions After the Hospital Asking Questions Summary Report

How can I decide what's best for my loved one?

Topics on this page:

- [Making healthcare decisions for someone else](#)
- [Thinking about the goals of your loved one's treatment](#)
- [Thinking about what your loved one would want](#)

Making healthcare decisions for someone else

It can be difficult and stressful to make healthcare decisions for another person. You may not really know what your loved one would want. But even if you do, it's not always a simple or clear-cut decision.

- You may need to make decisions quickly
- You may feel a lot of pressure from other people
- You may not have all the information you want to make an informed choice

In this section, we'll give you an overview of what it means to make healthcare decisions for someone else. We'll also help you think about what's most important to your loved one. You can use that information to help guide your decisions about their care.

What is a surrogate decision maker?

A surrogate decision maker (also known as a health care surrogate or health care proxy) is an adult who makes treatment decisions for a person who is unable to make their own decisions.

In some cases, a surrogate has already been named in a document called a [Durable Power of Attorney](#). When there is no Durable Power of Attorney, doctors may rely on a family member to serve as a surrogate.

How do I make healthcare decisions for someone else?

You might find it helpful to ask yourself these questions when making decisions for someone else.

- 1. What have they said in the past?**
 - Review any documents they have written about their wishes. These are sometimes called living wills or advance directives.
 - Think about any past conversations you may have had with them about what they might want.
 - As you are thinking about this, keep in mind:
 - Sometimes people may change their mind about the types of treatment that they would want.
 - Prior statements or documents may not apply to their current stroke. The health care team can help you decide if these apply to the current situation.
- 2. What would they want?**

If you are not sure about any past statements, then this is the most important question. Try to choose what your loved one would want if they were able to make the decision themselves. Sometimes it is hard to separate what they would want from what you may want, but it is important to try.
- 3. What do I think is in their best interest?**

If you are not sure what your loved one would want or how others would want to make the decision, think about what is best for your loved one.

b. Thinking about the goals of your loved one's treatment

Given the multitude of life-sustaining treatment decisions that a stroke surrogate decision maker may face (e.g. intubation, resuscitation, feeding tube), Understanding Stroke was designed to frame the decision as setting the overall goals of treatment rather than on any individual treatment or procedure. The overall goals of treatment were adapted from prior work (see manuscript references) and includes Life-Prolonging Treatment, Basic Treatment, and Comfort Measures Only.

Each treatment is organized into an accordion that can be expanded or closed depending on surrogate interest.

Thinking about the goals of your loved one's treatment

Before making specific decisions for your loved one, it helps to think about the overall goal of their medical treatment. While there are different ways to define the overall goals of treatment, it is sometimes helpful to think about this as 3 main categories:

+ Life-Prolonging Treatment

+ Basic Treatment

+ Comfort Measures Only

This table summarizes the 3 categories. You can click or tap on the colored bars above to read more about each category.

	Life-Prolonging Treatment Goal: Keep alive as long as possible	Basic Treatment Goal: Maintain physical and mental functions	Comfort Measures Only Goal: Maximize comfort and relieve pain
Cardiopulmonary resuscitation (CPR) and defibrillation (electric shock to the heart)	X		
Breathing machine (ventilator)	X		
Intensive Care Unit (ICU) care	X		
Intravenous (IV) therapy	X	X	Sometimes used for pain
Hospitalization	X	X	Sometimes
Physical, occupational, or speech therapy	X	X	
Pain relief	X	X	X

- Life-Prolonging Treatment

Goal: **help the person live as long as possible to allow time to recover from the stroke**

There are no limits to treatment and it includes everything a modern hospital has available to keep someone alive, such as:

- Using chest compressions and electric shocks to restart the heart if it stops beating
- Breathing machines (ventilators) if a person cannot breathe well on their own
- Other medical procedures that are done in the intensive care unit (ICU)

- Basic Treatment

Goal: **maintain physical and mental functions and allow time to recover from the stroke**

Some of the more intensive or invasive treatments may be limited. Treatment depends on the person's physical and mental functioning and may include:

- Intravenous (IV) therapies like antibiotics
- Hospitalization
- Physical, occupational, and speech therapy to improve recovery from stroke

Basic treatment **does not include** cardiopulmonary resuscitation (CPR), breathing machines, or intensive care unit (ICU) care.

- Comfort Measures Only

Goal: **maximize comfort and relieve pain**

- Treatment is only used to keep the person comfortable.
- Comfort care **does not include** cardiopulmonary resuscitation (CPR), breathing machines, or intensive care unit (ICU) care.
- Occasionally, intravenous (IV) medications or hospitalization are used.
- There are no attempts made to artificially prolong life.

c. Thinking about what your loved one would want

This section focuses on helping the surrogate clarify the patient's values. A list of situations where a patient might need help with activities of daily living is presented, and the surrogate is asked to pick up to 5 items that may cause their loved one to consider stopping treatment and choosing comfort measures only. A "None of the above" option is also offered for those who feel their loved one would not want to stop treatment under any circumstances. Their choices are recorded and saved into their Summary Report.

Thinking about what your loved one would want

People have different opinions about what makes life worth living. In this section, we'll try to help you clarify what your loved one would want so that you can make better decisions for them.

The list below shows some activities or abilities that can be affected by stroke. These may or may not apply to your loved one.

As you review the list, think about **which situations might affect your loved one's happiness or quality of life so much that they might consider stopping treatment to extend life and having [comfort measures only](#)**

- You may find that you think about each item differently, depending on whether the problem would be temporary or longer-term. For now, **try to think about what your loved one would want if they had these problems long term – for a few months or more.**
- The items you select will be included in your summary report. This list is to help guide your conversation with the health care team. It will not be used by itself to make treatment decisions. You can change your mind about these items at any time.

My loved one might consider stopping treatment to extend life (and choose comfort measures only) if, for a few months or more, they...

Select the most important items (up to 5)

- | | |
|--|--------------------------|
| Were not able to talk, but could still engage in non-verbal communication | <input type="checkbox"/> |
| Had difficulty thinking of words or understanding others | <input type="checkbox"/> |
| Were not able to breathe without the help of a machine | <input type="checkbox"/> |
| Were not able to participate in important hobbies, social, or religious activities | <input type="checkbox"/> |
| Had difficulty thinking clearly or making decisions (e.g. needed help managing finances) | <input type="checkbox"/> |
| Needed help from another person to eat, bathe, or take care of basic bathroom needs | <input type="checkbox"/> |
| Were not able to live on their own or take care of themselves | <input type="checkbox"/> |
| Needed a walker or wheelchair to move around | <input type="checkbox"/> |
| Had to stay in bed constantly | <input type="checkbox"/> |
| Needed a feeding tube to get nutrition | <input type="checkbox"/> |
| Had a lot of discomfort or pain | <input type="checkbox"/> |
| Had to stay in a nursing home or rehabilitation facility | <input type="checkbox"/> |
| Could not move one side of their body | <input type="checkbox"/> |
| None of the above. My loved one would want treatment to extend life in all of these situations. | <input type="checkbox"/> |

This activity has already been completed and saved to your Summary Report. You can print the Summary Report and bring it with you when you talk to the health care team. If you'd like to save different choices, you can print this page after making your selection. (Go to File>Print in your browser menu.)

In the Hospital

After the Hospital

VI. After the Hospital

a. Rehabilitation settings

A table with rehabilitation options is presented to the surrogate to help them determine what may be the best fit for their loved one. It is also briefly mentioned that there are treatments available to prevent another stroke.

b. Adjusting to life after stroke

Adjusting to life after stroke may be difficult for both the patient and their families. Resources are provided that may help with adjusting to a “new normal”.

The screenshot shows a website page with a dark blue header. The header includes the 'Understanding Stroke' logo, a font size selector (A A A), and navigation links for Resources, About, and Log out. Below the header is a dark blue navigation bar with links for About Stroke, Stroke Outcomes, In the Hospital, Making Decisions, After the Hospital (highlighted), Asking Questions, and Summary Report. The main content area has a light blue background and is titled 'What happens after the hospital?'. Below the title is a 'Topics on this page:' section with links for 'Rehabilitation settings' and 'Adjusting to life after stroke'. The 'Rehabilitation settings' section is highlighted with a dark blue bar. It contains a paragraph explaining that there are different types of rehabilitation services and that the best option depends on the severity of the stroke and other medical problems. Below this is a table providing an overview of common rehabilitation settings. The table has five columns: Services, Location, Frequency, and Generally best for. It lists six types of facilities: Acute rehab hospitals, Sub-acute facilities, Long-term care facilities, Outpatient facilities, Home health agencies, and LTACH (Long term acute care hospital). Below the table is a section titled 'Treatments to prevent another stroke' which explains that strokes are caused by risk factors that can be managed with medication or lifestyle changes. It also mentions that doctors and nurses can help understand the best way to prevent another stroke and that more information is available in the 'Resources' section. The 'Adjusting to life after stroke' section is highlighted with a dark blue bar. It contains a paragraph explaining that adjusting to life after a stroke can be difficult for both the person who had the stroke and their caregiver(s). It also mentions that resources are provided to help with adjusting to a “new normal”. Below this is a list of two bullet points: 'People tend to be stronger and more resilient than they realized.' and 'With time and rehabilitation, many people are able to adapt to new disabilities in ways that they could never have imagined before the stroke.' Below the list is a paragraph explaining that depending on how the loved one is doing, the surrogate may need to think about the future in a different way. It also mentions that there is a lot of support available, both online and from local resources, and that the surrogate should review the 'Resources' section for more information and a link to “Life after Stroke” from the American Stroke Association. At the bottom of the page are two dark blue buttons: 'Making Decisions' and 'Asking Questions'.

Understanding Stroke

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Resources About Log out

About Stroke Stroke Outcomes In the Hospital Making Decisions **After the Hospital** Asking Questions Summary Report

What happens after the hospital?

Topics on this page:

[Rehabilitation settings](#) [Adjusting to life after stroke](#)

Rehabilitation settings

There are different types of rehabilitation (“rehab”) services and they take place in different settings. Your doctors and therapists will help choose the best option for your loved one. It will depend on how severe the stroke was, other medical problems they may have, and their insurance.

The table below provides an overview of common rehabilitation settings.

	Services	Location	Frequency	Generally best for
Acute rehab hospitals	24-hour medical care; all types of rehab	Hospital	Several hours a day	People who can participate in rehab for several hours per day
Sub-acute facilities	Daily nursing care; many types of rehab	Rehab center or rehab unit of a larger facility	Long-term; less intensive than acute rehab	People with serious disabilities who may not be able to handle intensive rehab
Long-term care facilities	24-hour care; various types of rehab	Nursing home or skilled nursing facility (SNF)	2-3 days a week	People who require long-term nursing care
Outpatient facilities	Various types of rehab	Doctor’s office; rehab clinic	2-3 days a week	People who can travel to treatment
Home health agencies	Various types of rehab	Home	As needed	People living at home who cannot travel to treatment
LTACH (Long term acute care hospital)	24-hour intensive medical care	Hospital	Based on what the patient can handle	People who need highly specialized

Treatments to prevent another stroke

Strokes are caused by different risk factors that can often be managed with medication or lifestyle changes. There are many things that can be done to lower the chances of another stroke.

Your doctors and nurses can help you understand the best way to prevent another stroke. You can find more information about prevention in the [Resources](#) section.

Adjusting to life after stroke

Adjusting to life after a stroke can be difficult for both the person who had the stroke and their caregiver(s). People may have difficulty imagining what life will be like after a stroke.

As you consider what’s best for your loved one, try to think about their ability to adapt to any new challenges they may face after the stroke. Keep in mind:

- People tend to be stronger and more resilient than they realized.
- With time and rehabilitation, many people are able to adapt to new disabilities in ways that they could never have imagined before the stroke.


Depending on how your loved one is doing, you may need to think about the future in a different way.

There is a lot of support available, both online and from local resources you can get from your care team. Please review the [Resources](#) section for more information and a link to “Life after Stroke” from the American Stroke Association.

Making Decisions Asking Questions

VII. Asking Questions

This section gives the surrogate some tips on talking to the health care team, as well as a suggested list of questions they may want to ask. A free text field is also offered for them to enter any additional questions. Their choices are recorded and saved in their Summary Report.

A A AResourcesAboutLog out

[About Stroke](#) [Stroke Outcomes](#) [In the Hospital](#) [Making Decisions](#) [After the Hospital](#) **Asking Questions** [Summary Report](#)

Talking with the health care team

Topics on this page:

[Tips for talking to the health care team](#) [Your questions for the health care team](#)

Tips for talking to the health care team

- Take notes or record the conversation. Some people find it helpful to keep a daily log of conversations they've had with the health care team.
- Bring a support person with you.
- Let them know if you are confused. You can ask them to:
 - Repeat what they said
 - Slow down
 - Explain things differently
- Talk about your wishes for your loved one.
- If you feel that faith or religion may impact your decisions, you can bring this up with the health care team or speak to the hospital chaplain.
- Ask for the best way to contact them if you think of other questions later.
- Write down your questions. Some common questions are listed in the next section. You can add your own and print them out.

Keep track of your questions

You can use the space below to keep track of your questions for the health care team.

- Your questions will not be sent to the health care team, but will be added to your Summary Report.
- You can take a printout of the report when you speak to the health care team.

Here are some commonly asked questions. If you want to ask any of these questions, check the box to add them to your Summary Report

How long will my loved one be in the hospital?	<input type="checkbox"/>
Where might they go for rehabilitation?	<input type="checkbox"/>
What is the best way for family to support them?	<input type="checkbox"/>
What is the best way to help prevent another stroke?	<input type="checkbox"/>
What is my loved one's risk for having another stroke?	<input type="checkbox"/>
Can you tell me more about my loved one's chances of recovery?	<input type="checkbox"/>

Type in any other questions you have. Please do not include any personal identifying information (names, phone numbers, etc.)

This activity has already been completed and saved to your Summary Report. You can print the Summary Report and bring it with you when you talk to the health care team. If you'd like to add more questions, you may enter them now and print this page when you are done. (Go to File > Print in your browser menu.)

[After the Hospital](#) [Summary Report](#)

VIII. Summary Report

The Summary Report collates key information from the website into a report that the surrogate can print out and use in their conversations with the health care team.

The Summary Report includes stroke type, prognosis, results from the values clarification exercise, tips for talking to the health care team, a list of the surrogate's questions, as well as national and regional resources (not pictured).

An example for Ischemic Stroke is shown.

The screenshot shows the 'Understanding Stroke' website's 'Summary Report' page. The page title is 'Summary Report'. Below the title, a dark grey box contains the text: 'This Summary Report has information about your loved one's stroke and the activities you completed in the website. You can take a printout of this report when you talk to your health care team.' Below this, a yellow box says 'Topics on this page:' followed by several links: 'Your loved one's stroke type', 'Your loved one's predicted outcome', 'Your loved one's preferences', 'Tips for talking to the health care team', 'Your questions for the health care team', and 'Resources'. A dark grey header box contains the text 'Your loved one's stroke type'. Below this, the text reads 'Your loved one had an ischemic stroke.' An illustration shows a human head in profile with a brain. A yellow callout points to a specific area of the brain, stating 'Area of the brain injured from not receiving enough blood'. A circular inset shows a cross-section of an artery with a red blood clot blocking the flow, with a yellow callout stating 'Blood clot blocking blood flow in an artery'. The text 'ISCHEMIC STROKE' is centered below the illustration.

The screenshot shows the 'Your loved one's predicted outcome' section. It begins with the heading 'Intracerebral hemorrhage (ICH)' followed by a bulleted list: 'Also known as a "brain bleed" or hemorrhagic stroke', 'Less common type of stroke (about 10% of all strokes)', 'Occurs when a blood vessel breaks, causing blood to leak into the brain', and 'Pressure from this blood can injure other parts of the brain'. Below this, a dark grey header box contains the text 'Your loved one's predicted outcome'. The main content area has the heading 'Out of 100 people who have a stroke similar to your loved one, by three months...'. Below this heading are five columns of text, each with a large number and a description: 'About 22 will have mild disability or better', 'About 31 will have moderate disability', 'About 32 will have moderately severe disability', 'About 9 will have severe disability', and 'About 18 will have died'. At the bottom, there is a pie chart with five colored slices corresponding to the data above. A legend below the pie chart shows a small square and the text 'Show bar chart'.

Your loved one's preferences

These are the situations you felt would affect your loved one's happiness or quality of life so much that they might consider comfort measures only:

- Was not able to talk, but could still engage in non-verbal communication
- Was not able to breathe without the help of a machine
- Was not able to participate in important hobbies, social, or religious activities
- Needed help from another person to eat, bathe, or take care of basic bathroom needs

Choices above are from the first time this activity was completed

Tips for talking to the health care team

- Take notes or record the conversation. Some people find it helpful to keep a daily log of conversations they've had with the health care team.
- Bring a support person with you.
- Let them know if you are confused. You can ask them to:
 - Repeat what they said
 - Slow down
 - Explain things differently
- Talk about your wishes for your loved one.
- If you feel that faith or religion may impact your decisions, you can bring this up with the health care team or speak to the hospital chaplain.
- Ask for the best way to contact them if you think of other questions later.
- Write down your questions. Some common questions are listed in the next section. You can add your own and print them out.

Your questions for the health care team

- Other questions or concerns you have:
question ?

Choices above are from the first time this activity was completed