HHS Office for Civil Rights issues necessary proposed rule for health care

The COVID-19 pandemic has posed a horrible threat to the lives of all Americans—especially for people with disabilities who sought medical treatment but found appropriate care difficult, if not impossible, to obtain.

After these cases of disability bias were reported in states across the country, the US Department of Health and Human Services (HHS) Office for Civil Rights (OCR) proposed a new rule protecting the “fundamental human dignity of individuals with disabilities in the nation’s health care system.” The stated protections in the new rule include:

- Protect patients, including infants born alive whose parents or guardians consent to treatment from disability discrimination in Federally funded programs and activities;
- Protect patients, including infants born alive, from unlawful denials of emergency screening or stabilizing treatment in covered hospitals;
- Prohibit disability discrimination in the provisions or withdrawal of life-saving or life-sustaining care;
- Prohibit covered providers from basing certain life and death medical decisions on evaluations of the relative worth of the life of a patient with a disability, or on stereotypes or bias with respect to disability;
- Prohibit covered providers from exerting undue influence or steering patients toward the withdrawal of life-saving or live-sustaining care, or toward the provision of life-ending services such as assisted-suicide, mercy killing, or euthanasia, on the basis of disability and;
- Require hospitals to inform a patient or the patient’s legal representative if and when a “do not resuscitate order” is entered for the patient without consent under facility regulations. [HHS, Press Release, 1/15/21; HHS Rule, “Special Responsibilities of Medicare Hospitals in Emergency Cases & Discrimination on the Basis of Disability in Critical Health & Human Service Programs or Activities,” 1/14/21]

It is impossible to overstate the need to have this new proposed rule officially adopted. It clearly establishes protections in the health care system the Patients Rights Council, disability rights groups, and other patient advocates have spent decades promoting.

There is concern, however, that this rule, promulgated under the Trump administration, may not be finalized and adopted by the new administration for political or other reasons. Efforts have been made by multiple advocacy groups to convince the administration that this HHS rule is a major priority that needs adoption. Reportedly, OCR Director Roger Severino—who oversaw the creation of the rule—said he would leave the following message on his desk for his successor: The proposed rule “is too important to depend on political party or ideology.” [Bloomberg Law, 1/15/21]

Oregon, disability discrimination, and doctor-assisted suicide?

Last December, National Public Radio (NPR) ran a series of articles highlighting Oregon cases where seriously ill patients with disabilities were denied hospital care in 2020. According to Joseph Shapiro, author of the series, these patients were brought to various Oregon hospitals during the COVID-19 pandemic at a time when hospital beds and ventilators were readily available.

One case involved a woman with an intellectual disability who was taken to a hospital in Pendleton with COVID. The hospital denied her a ventilator that she needed, and the doctor, who determined she had a “low quality of life,” wanted her to sign a form permitting the hospital to deny her care even though she did not understand what he was asking her to do. Ultimately, both do-not-resuscitate and do-not-intubate orders were written by a medical provider. She was left without treatment for two days. With the help of the advocacy group Disability Rights Oregon (DRO), the woman, near death, was moved to another hospital. She was placed on a ventilator in ICU, recovered, and was returned to her group home.

In another case, a quadriplegic, 64-year-old man with an intellectual disability had a high fever and was taken to the hospital in Corvallis. ER staff refused to test him for COVID because, as one staff member said, it would be “waste of valuable PPE [personal protective equipment].” With pressure from his group home staff, the hospital finally tested him. He had pneumonia.

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Patients’ Rights

Everyday survival tips & other helpful suggestions

Part 1

This is Part 1 of a continuing series excerpted from a new booklet by the same name recently published by the Patients Rights Council.

When we hear about emergencies and natural disasters, it’s often easy to think that they are unusual. But that’s really not the case.

There have always been natural disasters such as hurricanes, floods, deadly fires and earthquakes that affected hundreds of people. In addition, there have been accidents and medical emergencies that families face all the time. And, of course, with the pandemic, the entire world has faced unprecedented changes.

While we hear about a return to a “new normal,” what we call “normal” really means there will be situations in which preparation for emergencies can mean the difference between life and death.

Wouldn’t it be a good idea to take some time to prepare for the possibility of such situations?

Have you ever heard of the “Serenity Prayer”? God, grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.

Those who attend Alcoholics Anonymous or Al-Anon meetings (meetings for the families and friends of alcoholics) are very much aware of it. But it’s equally applicable to anyone and to every situation.

It helps to focus on what we can do.

In this series, you’ll find some helpful information—information that may help you to prepare for the unexpected.

Protect yourself and others with the PRC’s Protective Medical Decisions Document

People often call the PRC to request the durable power of attorney for health care, called the Protective Medical Decisions Document (PMDD), for a family member who is going into the hospital for surgery. That, of course, is a very important thing to do.

Yet, when asked if they have such a document for themselves, they often say “no.” If they’re asked who would make decisions for them if they’re in a serious car accident driving to visit that relative in the hospital following surgery, the response is usually, “I never thought of that.”

We discuss how important it is for every person who is 18 or older to name someone they know and trust—who agrees with their views and values and can be assertive on their behalf—to make medical decisions for them in the event they’re ever unable, either temporarily or permanently, to make those decisions for themselves.

So, when protecting others, it’s really important to protect yourself.

It’s much like what you hear in the flight attendant’s announcement when traveling by air: “If the oxygen masks descend, put yours on first, so you can help others around you.”

Note: The PMDD is one type of advance directive. It should be noted that while an advance directive is very important, you cannot be required to have such a document. It is a violation of both state and federal law for any facility that receives even a penny of Medicare or Medicaid money to require that any patient have an advance directive.

Read before you sign

Have you recently been to a scheduled doctor’s appointment or had elective surgery? And, when you checked in, were you given a number of papers to sign?

Most people sign such paperwork with little or no thought. However, that can be a real problem.

Think of it this way: If you were signing a contract for a home or a car, would you read it carefully before signing it? Chances are, the more expensive the item, the more carefully you’d read every word. Yet, when you are signing papers for medical treatment, you are dealing with your life.

Not every paper you’re given must be signed and, even those that must, may contain words or phrases that you do not want in them. You have the right to cross out words or to add additional words.

But, realistically, when we’re at the appointment or checking into the hospital, we’re generally not concentrating on reading paperwork. That’s why it’s important to ask for the paperwork in advance so you can carefully read it at home and decide whether you want to sign it.

Ask questions

If a health care provider says something you don’t understand, ask for an explanation. You have the right to know exactly what is meant so that you can give or withhold informed consent.

What if you didn’t review the paperwork before signing?

Often, people do sign papers in a doctor’s office or at an urgent care facility without reading before signing.

If that has happened to you, it’s important to go back and ask to review what you signed and to delete or change anything that is not accurate.

Review your other medical records

It is your right to review your medical records. That way, you can update any information that is important to your care or ask your health care provider about prescriptions or test results that are missing or incorrect.

This is particularly important to make certain that you haven’t inadvertently signed a document that you don’t want.

In the past, medical records were kept by a person’s primary care provider. But that has changed. Often such records are stored electronically. So, you may need to request those electronic medical records (EMR) and obtain copies for yourself.

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New year brings renewed attempts to legalize & expand planned-suicide deaths

It’s the beginning of 2021, the time when the yearly tradition of new bills to legalize doctor-prescribed suicide are introduced in state legislatures targeted by assisted-suicide supporters.

Last year must have been a nightmare for those supporters. By early April, nine of the states with prescribed-suicide bills to consider had already defeated those measures.

Then, when it became evident that the COVID-19 pandemic was taking a serious toll across the country, state legislators in the remaining targeted states decided to close their legislative sessions before the assisted-suicide related bills could be heard in committees. As a result, all bills in 2020 to legalize assisted death or expand the reach of existing assisted-suicide laws died in Arizona, Connecticut, Delaware, Florida, Hawaii, Indiana, Iowa, Kentucky, Maryland, Massachusetts, Minnesota, New Hampshire, New York, Pennsylvania, Rhode Island, Utah, Virginia, Washington State, and Wisconsin.

Now, it is a new year and planned-death activists—groups like Compassion & Choices (C&C) and the Death with Dignity National Center (DWDNC)—have been busy finalizing campaigns for the passage of a new round of bills.

According to C&C, there are “lawmakers sponsoring bills in approximately 20 states where we are organizing and working alongside coalitions to move legislation forward.” [C&C Magazine, Fall 2020] The DWDNC has formalized what it calls “Our SouthWest Strategy,” focusing especially on three states: Arizona, Nevada, and New Mexico.

Opponents of doctor-assisted suicide have also been working hard educating and preparing state coalitions for legislative battles.

As of January 26, prescribed-suicide related bills have been introduced in four states: Arizona (HB 2254), Indiana (HB 1074), New Mexico (HB 47), and New York (A 198, a study bill). Opponents also anticipate that there will be additional legalization measures considered in Connecticut, Delaware, Maryland, Massachusetts, Nevada, New Hampshire, New York (in addition to the above study bill), and Virginia.

While 2021 bills will be modeled on Oregon’s assisted-suicide law, they will likely eliminate some of the safeguards that were included in the Oregon law in 1997 in order to get it passed. Emboldened advocates now see these protective provisions as overly restrictive barriers to death access for patients.

Even states where doctor-assisted suicide is legal will be targets for less restrictive law changes. Washington in 2008 and Hawaii in 2018 passed Oregon-style laws. Now, Hawaii (SB 323) and Washington (HB1141) have bills that would significantly shorten or altogether eliminate waiting periods that allow patients time to reconsider their death requests. They would also expand planned-death access by authorizing non-physicians (physician assistants and nurse practitioners) to take on the doctors’ roles in the death-producing practice. Oregon is also expected to see expansion bills this year.

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Everyday survival tips & other helpful suggestions cont. from p. 2

According to the Health Insurance Portability and Accounting Act (HIPAA) you have the right to information whether stored electronically or on paper. That information includes doctor’s handwritten notes, diagnostic results including medical test results, lab reports, billing information, etc.

Access to some records may be denied. Those mainly include certain mental health records.

If you are seeking your medical records, it’s best to do so in writing. To make a request include your name, Medicare number if you are on Medicare, date of birth, address, phone number, a list of records you are requesting and the delivery option you want (by mail, fax, email, etc.).

It may take some time to receive this information. It’s important to know that you may have to pay a reasonable amount for those records.

Once you receive them, check to make sure the information is correct and complete. If not, you can ask your doctor to fix it. Your doctor may not agree, but you have the right to have your disagreement added to your records.

NOTE: In the next issue of the Update, Part 2 of this survival tip series will include information on the Physicians Orders for Life-Sustaining Treatment form (known as POLST or other acronyms like POST, MOLST, MOST, etc., depending on the state) and helpful suggestions regarding hospital stays and hospice programs.

Oregon, disability discrimination, and assisted suicide? cont. from p. 1

not COVID. When he recovered and was discharged, a doctor called the group home and recommended that the home stop the man’s care and his tube feeding and enroll him in end-of-life hospice care. [NPR, 12/21/20]

These discrimination cases are not isolated. According to Jake Cornett of DRO, “for a single state to have multiple cases like this coming up over and over, it should raise the alarm bell.”

And it did with State Senator Sara Gelser, who has a son with an intellectual disability. She told host Noel King on NPR that she was getting calls from across the state about similar cases. “I think people tend to think that these are just dystopian stories that would never happen,” she said. “But they do. And they have. And they will.” [NPR Transcript, 12/21/20]

Sen. Gelser authored SB 1606, a bill that was signed into law last year. It bars doctors from forcing elderly or disabled patients to sign do-not-resuscitate or do-not-intubate orders as a condition for hospital admittance or treatment. This is an important step in the battle against medical bias in the state.

The NPR series on this discrimination caused The Hill’s op-ed writer Merrill Matthews to question if Oregon’s legalization of doctor-assisted suicide 20 years ago had precipitated this medical bias. When the law passed, many argued it would cause the lives of disabled and elderly patients to be devalued. “I don’t know,” Matthews wrote. “But I do know that 20 years ago many people predicted and feared it.” [The Hill, 12/25/20]
News briefs from home & abroad...

**Canada:** The Canadian Parliament has been struggling to expand the country’s 2016 euthanasia law to comply with a September 2019 ruling by Quebec Superior Court Justice Christine Baudouin. She struck down the law as unconstitutional because it limited access to medically assisted death (MAID) to only terminally ill patients whose natural deaths are foreseeable. The court challenge was brought by two patients with disabilities who argued that their irremediable conditions caused them intolerable physical and mental suffering, but they were denied MAID because they weren’t terminally ill. Justice Baudouin gave the Federal government six months to amend the original law, but lawmakers could not meet the deadline. The government had to ask the court twice to extend the deadline. Currently, Parliament has until February 26 to come up with a new law.

The proposed new law (referred to as C-7) would greatly expand access to MAID. It creates a two-tier protocol with different “safeguards” to deal with the natural death-timing issue. Those patients whose natural deaths are foreseeable, would no longer have to wait 10 days between requesting MAID and their induced death. The requirement that patients give final consent just prior to being administered the lethal drugs may be waived for this group. If deaths are not foreseeable, a 90-day waiting period is required unless two doctors or nurse practitioners think the patient’s ability to make an informed decision will be lost before the 90 days are up. For both categories of patients, the mandate for two independent people to witness the patient’s signing of the death request is reduced to only one witness. The disability community has been very vocal about its strong opposition to these proposed changes in the law and the real threat they pose to vulnerable patients, including the elderly.

While C-7 does not expressly allow MAID for mentally ill individuals or dementia patients with advance death directives, these issues are expected to be debated in a mandated—though not yet scheduled—5-year review of the original MAID law by Parliament.

**New Zealand:** Last October, voters in New Zealand opted to legalize euthanasia and assisted suicide. The official results of the referendum, released on November 6, showed that 65% voted in favor of legalization and 34% cast their ballots in opposition to it. The new law, titled the “End of Life Choice Act,” (EOLCA) will take effect on November 7, 2021. Those eligible for a medically induced death must be 18 years-old or over, be a NZ citizen or permanent resident, have an irreversible terminal illness with a prognosis of 6 months or less, be experiencing unbearable suffering that can’t be relieved in a way the patient feels is tolerable, and must be competent to make an informed death choice. Individuals will not be eligible if they simply have a mental disorder or illness, dementia, or are elderly but physically healthy.

A revealing nationwide poll conducted by Curia Market Research just prior to the referendum vote found that the majority of voters were confused about what the EOLCA would legalize. Only 20% of those polled knew that the EOLA was not about legalizing the removal of life-sustaining machines or withdrawing unwanted medical treatment (actions already legal), only 35% knew that the EOLCA allowed terminally-ill patients with no physical pain to be euthanized, and only 13% knew the act did not require independent witnesses to safeguard patients against abuse or coercion. [Euthanasia-Free NZ, Press Release, 10/30/20]

**Other global hotspots:** On 12/11/20, Austria’s Constitutional Court ruled that the country’s law against assisted suicide is unconstitutional because it violates an individual’s right to self-determination. Lawmakers now have to pass a law implementing the ruling that will take effect on 12/31/21. Last year, Portugal’s Parliament passed a bill to legalize euthanasia and assisted suicide, but the country’s president can still veto it. Spain’s lower house of parliament also passed a euthanasia bill that is awaiting further action in the Senate.

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Please contact your tax advisor and attorney to learn how you can use planned giving to leave a lasting legacy to the PRC. If you then decide to proceed and would like to discuss the possibility of a planned gift with us, please contact:

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