

Maggie Kuhl:

Hi everyone. Thank you for joining us. My name is Maggie Kuhl. I'm director of research communications at The Michael J. Fox Foundation and today we are discussing the topic that is dominating the news and most of our lives these days, the coronavirus. If you tuned in hoping to hear a discussion, instead, on what we originally planned to focus on today, environmental factors related to Parkinson's, please know that we will cover that in a future webinar. So, stay tuned for more on that. But today, we want to talk about the coronavirus. And before I introduce our expert panel, I just want to answer the question that we've been getting constantly, which is are people with Parkinson's at higher risk of coronavirus? And the answer is, right now, there's no reason to believe that Parkinson's itself raises the risk of the coronavirus. We'll talk much more about this, but I just wanted to start off making that statement.

Maggie Kuhl:

So, let's jump in. And today, we're going to cover what we do know about the virus, and how it could affect people with PD, how social distancing might help prevent the spread, and what we can do to manage the challenges both of this medically and of this social isolation time that we all find ourselves in. We're also the Michael J. Fox Foundation for Research, so we want to touch on the potential impact on Parkinson studies and our ongoing efforts to find new treatments, and a cure for this disease.

Maggie Kuhl:

I'm honored to introduce an amazing panel today. I'm really grateful for them all taking their time to share with us their expertise. Today, we have Dave Aronoff from Vanderbilt University who leads their division of infectious diseases. Dr Aronoff. Thanks.

Dr. David Aronoff:

It's a pleasure.

Maggie Kuhl:

And we have Katie Leaver from Mount Sinai in New York. She's a movement disorder specialist who sees patients and practices research. And she'll be sharing with us her experiences. Hi Dr. Leaver, thanks for joining us as well.

Dr. Katie Leaver:

Happy to be here.

Maggie Kuhl:

Great. And Carly Tanner is on the other coast, another hotspot of the virus, in San Francisco. She is a professor of neurology at UCSS and director of the Parkinson's Center at the San Francisco Veteran's Affairs. She also sees patients, and her research covers a wide range of Parkinson's therapies, and understanding including the epidemiology and the genetics of the disease. So, Dr. Tanner, thanks ...

Dr. Carly Tanner:

Oh, thanks very, I'm really pleased to be able to be here, right.

Maggie Kuhl:

We're very, very glad you could join us as well. And Ted Thompson from our team. He leads our public policy department and he'll talk to us a bit about what the government is doing in response to this virus and some of the modifications that could help provide care and medications to people with PD. Hi Ted, thanks for being on today.

Ted Thompson:

Glad to be here, thank you.

Maggie Kuhl:

All right, so, let's start with what we do know about the virus. Dr. David Aronoff, why don't you just give us kind of a lay of the land of what we're facing with this disease today?

Dr. David Aronoff:

Sure. I'd be happy to. And, again, it's an honor to be able to participate. I think this is really an active moving target and there's a lot we know, but there's a whole lot we don't know. This is a small virus and it causes respiratory infections. We're most concerned when it causes pneumonia and it, generally, will cause a cough, and sometimes shortness of breath, fever. But in the vast majority of people who get infected it really is a pretty mild, self-limited illness. Right now, we think there have been over 200,000 cases documented across the world and a small, but significant number of patients have had severe illness and, as we're hearing in the news, some have died. So, it's a really striking spectrum of symptoms ranging from really nearly asymptomatic to kind of a nuisance, to putting people into the hospital, to killing people.

Dr. David Aronoff:

And so, that coupled with the fact that it seems to be very transmissible we've seen it all. We're all watching the news and watching the internet. And here's something that cropped up really at the beginning of the year that is now global. It's really, what we call, a pandemic has also been striking. And it's been a great opportunity to see how public health systems respond, how scientists and the public, and the healthcare sector can communicate in real-time. And I think it's really testing a lot of those systems in ways that we're going to learn from and, hopefully, continue to improve public health as a result.

Maggie Kuhl:

You said that the disease is very transmissible and I do want to talk about that for a minute, but first I wanted to focus on the vulnerable populations. You said that the response to the infection can vary wildly, so what do we know about who could, perhaps, have a more serious response to the illness, and what does that mean for them? What are these vulnerable populations?

Dr. David Aronoff:

Yeah, again, a really good question. And what we're learning, particularly from the experience in China and South Korea and Italy, is that anybody of any age is susceptible to getting infected by this coronavirus. As far as we know, this is the first time this particular coronavirus has been in human population, so we don't know a lot about how it behaves. But those who are getting more severe illness, needing to be hospitalized, developing pneumonia, or even requiring mechanical ventilation tend to be older adults among our populations. So, once people get above the age of 60 it seems that in and of itself, and we don't really understand fully why this is the case, but it seems that being on the older age

range of the spectrum is a major risk factor for having more severe disease than being young. It's increasingly apparent that even young children can get symptomatic disease, but when we look at a risk factor for severity age, right now, is perhaps the most important.

Dr. David Aronoff:

What we're also learning though is that people who have medical health problems that compromise their immune systems also seem to be at increased risk for severe disease. So, imagine patients who are undergoing chemotherapy, for example, for cancer, or people who have received organ transplants, or bone marrow transplants. Even some metabolic disorders, the most common being diabetes seems to be a risk factor for having worse outcomes. So, perhaps not surprising, but young healthy people seem to be the most resistant to getting severe disease. And older, or more chronically ill, or immunocompromised populations seem to be at increased risk.

Maggie Kuhl:

And we'll talk a bit about this more on the next slide, but a lot of people are asking if people with Parkinson's disease fall into those immunocompromised groups? I mentioned you didn't include them in your list, but Dr. Tanner, what do you know about the potential risk for the Parkinson's population of contracting COVID-19?

Dr. Carly Tanner:

Yes so, as far as I know, there is nothing particular about having Parkinson's disease that makes people especially vulnerable. Many people with Parkinson's disease are in the age at risk, and it is a chronic illness, and it does affect other kinds of ways of functioning. So, I think it's sort of prudent to take precautions and think of oneself, if you have Parkinson's, as being someone who should take special care. But I'm not aware of any particular reason that people with Parkinson's per se should be singled out.

Maggie Kuhl:

And Dr. Tanner, sticking with you, I received a question from someone who'd registered asking how to know if the symptoms are from Parkinson's or from coronavirus? And looking at this list, it doesn't seem like they overlap much, but can you comment on that?

Dr. Carly Tanner:

Yes, I think that's right. Parkinson's disease symptoms really don't overlap with symptoms of coronavirus, which are really the cough, shortness of breath. I'll leave that to Dr. David Aronoff to outline everything, but those aren't typical Parkinson's symptoms. Some people who have certain features of Parkinson's that, for example, make it harder to swallow might want to be particularly thoughtful because that could be something that leads to coughing. And so, thinking about your usual day-to-day symptoms compared to anything different, but I think especially fever would be a signal that this would be something to pay attention to because this is not Parkinson's disease. Defer a little bit to Dr. David Aronoff if he has additional comments.

Dr. David Aronoff:

This is, yeah, David Aronoff. I completely agree. I think the main issue with this particular infection is that it's causing new cough, or new shortness of breath and sometimes fever, and can be associated with things like sore throat or muscle aches and pains, and fatigue. And for people who have Parkinson

disease, these would generally be different from their normal symptoms, and would really represent a new problem.

Maggie Kuhl:

Understood. Dr. David Aronoff question for you, as I said, you had shared that this is pretty transmissible. Can you say more about how the virus spreads and how we might test for it? I think that's a big concern in the population is that there's not enough tests. There's not a way to be easily tested. As you'd said, there is an asymptomatic period, or perhaps your entire duration with the disease, so you could be carrying it. So, in addition to how it's spread, where we are with testing and then Ted, I'd love to bring you in too and hear what the government's doing about that. So Dr. David Aronoff, why don't you kick us off please?

Dr. David Aronoff:

Yeah. So this is a virus that is spread through respiratory droplets, which are generally disseminated when we sneeze or cough. So, symptoms are really an important driver of transmitting the disease. But even small respiratory droplets come out of our mouth when we talk to people, or breathe heavily laughing, et cetera. We think that people who have no symptoms don't have as much virus coming out when they talk, or are interacting with people than someone who clearly has a deep cough. So, symptoms are probably very important for driving the airborne transmission. And we think the range of that transmission is about six feet. And that's why you may have heard in your communities to try to space yourself from others about six feet apart.

Dr. David Aronoff:

But the other thing that we're learning about this is that the virus itself can stay infectious for hours to days even on surfaces, tables, doorknobs and, of course, hands and faces. And so, that's where we've really been trying to emphasize cultural changes around social distancing, and using good hand hygiene, and trying not to engage in the usual greetings of direct handshakes, or kisses on the cheeks, or hugs. But to think more creatively about ways to greet people that don't involve physical contact.

Dr. David Aronoff:

And the reason the hand hygiene is so important is because we think that people ... well, we know I'm certainly victim of this, that people inadvertently touch their face, touch their eyes, touch their mouth, touch their nose during the course of a day. And so, limiting that really does make a difference in terms of limiting transmission. It is a challenge to diagnose these cases of people who have been inoculated or infected with virus but don't have symptoms yet. A big barrier to knowing exactly who has the coronavirus is number one, it seems that we shed so little virus when we're asymptomatic that the diagnostic tests probably don't work all that great when we're completely asymptomatic.

Dr. David Aronoff:

And number two, we don't have enough diagnostic facilities and tests to really test everyone who doesn't have symptoms, but is wondering if they have been infected. And even we don't have enough facilities and tests to start testing people who have developed new symptoms that are concerning. And that's a changing variable because in my neck of the woods, here in Nashville, Tennessee, we at my institution and others are working really hard to increase our capacity to be able to do testing. But, right now, what we're generally advising people is to contact their healthcare providers if they have symptoms that are worrisome for this infection, which we've called COVID-19, and asking where they

have testing facilities, trying to get an idea for what the wait times are, and trying to decide how the answer to that test is going to change behavior.

Dr. David Aronoff:

I think, for now, it's important for all of us to behave as if even when we feel well that we may be carrying this virus, and may be able to transmit it. So, we need to be engaging in social distancing and hand hygiene, et cetera. And if we get a mild illness, to be sure that we're sequestering ourselves away, isolating ourselves away from others is as much as we can. And trying not to burden the healthcare infrastructure, like the emergency departments, urgent care clinics and primary care clinics, in-person looking for a test unless we really think we'll need to be potentially in the hospital, or get some other sort of direct care. But right now it's a big challenge.

Maggie Kuhl:

And a challenge, Ted, that the government is paying attention to and devoting some resources to. Can you share any developments on additional funding, or efforts to try and develop new tests, or treatments?

Ted Thompson:

Yeah, sure. Well, clearly, everybody knows this is extremely fast moving and hour by hour. There's new news nationally, internationally, or at the state and local level. So, at this point, the government is fully galvanized at the federal level invoking laws that hadn't been used in decades in order to try to address the shortages of things like ventilators, gloves, masks. In fact, the CDC has now put out guidance on homemade masks because of the severe shortages. The Pentagon is now involved, they are releasing masks and ventilators that they have stockpiled. So, all parts of the federal government are galvanized around it.

Ted Thompson:

The president, recently, declared a national emergency, which enables spending of roughly \$50 billion of emergency funding to go to the state and local governments to address capacity issues. In the national emergency as well, and this is more specific to Parkinson's patients access and care, he waived a great number of rules and regulations around telemedicine. And so telemedicine for Medicare is going to be covered. So, you will be able to see your doctor virtually, if you and your physician have that capability. So, the recommendation there is check in with your healthcare provider to see if they have that capability because that would go a long way to continue to have you not in the public, possibly exposed. And the treatment for regular check-ins and things like that have been shown to be very effective.

Ted Thompson:

One thing I wanted to point out, because we've been talking about age quite a bit, the CDC did an analysis of cases from February 12th through March 16, and the data suggests that younger people are pretty highly at-risk. It showed that 38% of those sick enough to be hospitalized were under age 55. And, as others have mentioned on here, we all could be carriers but we may not show symptoms, and taking this seriously and maintaining of social distancing, avoiding going out in the public, things like that are critically important. And the government is telling us to do that. And the response by governments, plural, differs: state, local, federal. Some states, frankly, have not galvanized very well and have minimized this disease. I would strongly encourage anybody to rely on CDC, HHS, reputable websites

that are based on science, and try to avoid some of the mania that's going on in social media that will help with your state of mind.

Maggie Kuhl:

Definitely. And CDC is the Centers for Disease Control and prevention. And HHS is the US Department of Health and Human Services.

Maggie Kuhl:

So, we have covered a lot in this first slide and we're going to talk more about things like telemedicine and social distancing a bit. I do want to move on, and talk about how the coronavirus is impacting people with Parkinson's, if they do contract the disease. And Dr. Leaver, thanks for your patience. Want to bring you in here, and curious how your patients have been reacting, what you've been telling them about the raised risk of contracting the virus, and if they do have symptoms or do have a test and test positive, what does that mean for people with PD?

Dr. Katie Leaver:

Yes, hi. And I'm looking at the slide and do agree with things listed there. So, as Dr. Tanner said, we don't think that Parkinson's disease in and of itself does increase the risk for contracting the virus. However, it is like other illnesses within this patient population wherein, if you contract an illness and you feel sick you may notice a temporary change, or worsening in your Parkinson's symptoms. Whether those are the motor symptoms of tremor, whether they're the non-motor symptoms of anxiety ... I mean, I think there's a lot of anxiety surrounding this anyway, but you may see this temporary increase in Parkinson's symptoms while you are feeling ill. But it's important to know ...

Dr. Katie Leaver:

While you are feeling ill, but it's important to note that once you start to recover and improve, the Parkinson's symptoms that were worsened should return to baseline. I try to emphasize and reassure my patients that if you see a change, it's not because the Parkinson's disease has been affected at basic level or that there's a sudden worsening and progression. It's more that you just need to be patient with things, give yourself some time to recover, and you should be back to baseline once you feel better from the viral symptoms. [crosstalk 00:21:38]. Yeah, the cough and cold medicine?

Maggie Kuhl:

[crosstalk 00:21:44]. Let's focus just on getting the disease and the experience if you do for a second because I had a question come in on if you do contract the virus with Parkinson's disease, will it take you longer to recover because perhaps you're weakened from the Parkinson's.

Dr. Katie Leaver:

Yeah, that's a great question. It's something I wanted to bring up as a reminder of how diverse our patient population is. As everyone knows, there's a huge spectrum of Parkinson's patients and disease manifestations. There are a lot of young people who are very healthy who also have Parkinson's disease and in those cases, I would say no, they're at the same risk as the general population of young, healthy people. But I think once you start developing more advanced disease and you have some degree of fragility or you feel more weak, it may then take you longer to recover, but that's similar to the flu or any other kind of bacterial illness.

Maggie Kuhl:

Understood. Dr. Tanner, anything else to add from what you've been seeing in your patient population or questions that your people with PD whom you see are asking?

Dr. Carly Tanner:

No, I agree with everything that's been said. I think if you have Parkinson's disease and you get even a cold, your symptoms can worsen and your fatigue can be greater. Other features can get worse for a period of time, but it's not permanent. It's during that period of time and there's no reason to think that this particular illness would make your Parkinson's worse longterm.

Maggie Kuhl:

That's good. If you do have an issue with your Parkinson's disease, a serious symptom comes up, or you have a fall for example, we know people with Parkinson's are increased risk for falls, what is the safety or the guidance on seeking medical care? I think a lot of people are concerned about going to an emergency room and contracting Coronavirus when they perhaps have a pretty serious non-related condition. Dr. Tanner, what would you tell your patients about that?

Dr. Carly Tanner:

Yeah, I would first of all say this is region by region. So where I live right now, everyone in the population is advised to shelter in place unless they're part of an exempt professional category. I live in the San Francisco Bay area and all the counties surrounding have that in place for a long time until the beginning of April. So I think it's very important to know the national but also the regional situation and then be in touch with your local healthcare system or with your physician, your neurologist, your primary care doctor to get advice on the best way to approach it. Our university has separate respiratory screening clinics that have been set up at all of our hospitals that will handle the Coronavirus suspect cases, and the regular emergency room therefore is relatively protected from that so that people with other health emergencies can also be treated. So I think hospitals are working really hard to come up with ways to address this. There are constant meetings and changing situations are taken into account. [crosstalk 00:25:30]. I would say check in with your physician. Yeah.

Maggie Kuhl:

Great. That was going to be my takeaway. Check in with your-

Dr. Carly Tanner:

[crosstalk 00:25:38] physician, yeah. Yeah.

Maggie Kuhl:

Your local. Understood. Dr. [Leiber 00:25:42], you had brought up the medications. If you do experience symptoms, you perhaps may want to take a cold or cough medication, but there actually could be some interactions with some Parkinson's drugs. Could you comment on that for us?

Dr. Katie Leaver:

Yes. I think as a general rule, we advise our patients to let us know as their physicians if they're going to be taking new medications, but specifically I think this question comes up which medications specifically. When I talk about cough medicine, the exact compounds that have an interaction is something called

dextromethorpan. It's in a lot of these over-the-counter cough medicines. It's a cough suppressant. That can have interactions with the commonly known drug Azilect or rasagiline which I know a lot of our patients are on. It doesn't mean that you can't take dextromethorpan at all, but usually I advise patients to modify their Azilect. Every physician may be giving different advice, but because of this, I do advise people to call their physician and discuss it before taking an over-the-counter cough or cold medicine.

Maggie Kuhl:

Dr. [Erinoff 00:27:04], bringing you back in, there's been a lot of coverage and controversial reports around taking ibuprofen or NSAIDs and their potential worsening of COVID. Can you comment on that?

Dr. David Aronoff:

Yeah, sure. I'd be glad to. These reports came out of France. We don't have really any access to data to know really more about just what's been verbalized or put on social media that apparently patients either take drugs like ibuprofen, what we call nonsteroidal antiinflammatory drugs or NSAIDs on a chronic basis, maybe an increased risk for severe COVID illness or it may be that patients who are treating symptoms during the illness are at risk for worsened disease. Without data, it's really hard to know what the make of that. My recommendation currently which I think is shared by others is not to tell people who are stable on those types of medicines to do anything different right now.

Dr. David Aronoff:

The reason this can get very confusing is that people who don't feel well take these medicines. The people who feel worse tend to be the most sick and they tend to take more of these medicines. So it can look like the medicines themselves are causing the illness to be worse when really it's a horse and buggy or horse and cart kind of issue where the whole reason they were taking more of the medicines is that they were feeling worse. So it's hard to separate these, and right now we really don't have a good understanding of whether medicines like ibuprofen are to be avoided.

Dr. David Aronoff:

In general, what I would tell people is limiting the number of medicines that you add to what you're already taking is always a good idea. When you're sick, it's a good idea to be engaged with a healthcare provider about any new medicines that you're wanting to take or a pharmacist for example. That could be important for the use of medicines like ibuprofen which that class of medicine can cause harm to the kidneys. It can cause stomach ulcers. So for people who already have chronic kidney problems or are at risk for stomach ulcers, those drugs may not be good for them regardless of the presence or absence of COVID. So drugs like acetaminophen may be safer. On the other hand, acetaminophen can be associated with liver toxicity or hepatitis if taken in abundance or given to somebody who has preexisting liver disease. So I always say if you're somebody who's chronically ill or you're already taking a lot of medication, if you're going to add any new medicine even for temporary symptom relief, it's good to run it past a pharmacist or your healthcare provider first.

Maggie Kuhl:

Understood. Just to clarify, the acetaminophen is the brand name Tylenol over the counter?

Dr. David Aronoff:

That's exactly right. Yeah, and it's a tricky one because acetaminophen is also a drug that's used in a lot of combination medicines like NyQuil or Excedrin or Theraflu. So it's important for patients to know if



they may be getting double doses of medicines like acetaminophen by looking carefully at the labels of some of these medicines that contain mixtures.

Maggie Kuhl:

Got it. As always, work with your doctor for your own individualized responsive treatment. One more medication question before we move on, and Ted, I'll ask you to comment first and others might have thoughts too. There's been a lot of concern among our viewers around the shortage of, potential shortage of the drugs that they commonly take for their Parkinson's, their Sinemet, their Azilect, [rimantidine 00:31:10]. Manufacturing and distribution chains may be disrupted because of the virus. Ted, what is going on with drug supply and is the government doing anything in monitoring that?

Ted Thompson:

Excuse me. Yes, they definitely are monitoring and the FDA, that's one of its core functions, to determine whether there are shortages and work to address that. I do think with all the emergency powers that the federal government has currently and other national governments, that they seriously want to get a handle on that so that a really bad situation doesn't get even worse. The other topic related to that though is your own personal supply of medication. I know that some people are concerned about whether they're going to be able to get to the pharmacy, and a lot of insurance plans don't allow you to have more than a 30 or 60-day supply. A lot of those plans are now waiving that, allowing increased supply so that you don't have to leave the home. Many, many pharmacies are now also offering free home delivery during this period. So if you've got concerns about these things, you should call your insurer to find out what the policy is or they might have it on their website. Of course, check in with your pharmacy to see if they have free home delivery so that you don't actually even have to leave the house.

Maggie Kuhl:

Yeah, I think everything is changing these days. So don't make any assumptions that you know how a policy is structured because it might have changed even within the last hour. Okay. Let's move on to the next slide. We are going to show a visual that I'm sure many of us have seen, this flattening the curve. Dr. Erinoff, you commented before about not pursuing potentially elective procedures or diagnostic tests if you don't truly need them at this time because the healthcare system is being taxed very much so. Can you walk us through what we're seeing on the screen and how some of our protective measures might help manage this pandemic?

Dr. David Aronoff:

Yeah, sure. I'm delighted to. This is a really, I think, elegant representation of what we hope to accomplish for public health good by having people be relatively isolated right now. That's this concept of flattening the curve. So what you're seeing here is this concept that we know a lot of people are going to get infected with this virus. We've seen that play out in China and Korea and Italy, Europe, and now in the United States. It's so rapidly spreading. If we assume that a significant proportion of those people that get infected are going to require healthcare, they're going to require coming to a healthcare provider or a hospital or a clinic. You can imagine that if everybody gets infected in a very brief amount of time, that that is going to absolutely overwhelm our capacity to care for patients in an optimal way, things like running short on mechanical ventilators or even running short on reagents to test or medications to give our patients.

Dr. David Aronoff:

So one of the best ways that public health can help prevent the number of cases from exceeding the healthcare system capacity which is that dotted line on the chart is to try to slow the spread. Even working from the assumption that the total number of people who get infected won't change, which we actually hope it will, but if it doesn't change, the idea is to put up roadblocks against the virus so that it cannot spread across the population quickly. That gives us in the healthcare system time to respond and be able to provide the best care we can to each individual person. That's the flatter blue [inaudible 00:35:23] so to speak on this graph. If we're using protective measures, and this is all down to the individual level of staying at home, of using good hand hygiene, of not coughing onto your hands, of all the things that we talked about, that we may be able to slow down in a meaningful way the spread of this infection.

Maggie Kuhl:

Understood. Dr. Tanner, I'm interested to hear from you first. You'd mentioned the San Francisco shelter in place. What is your university doing in care and protective measures? Just curious from the front lines what you're seeing.

Dr. Carly Tanner:

Yeah, so what we have done is we've basically converted our visits to remote visits. So for people who have the capacity, we're doing telemedicine visits. So I'm seeing people through our computer video evaluation and able to do almost a complete exam actually for Parkinson's disease and then make recommendations just as I would if they had come in to the office. For people who don't have that capacity, we are speaking with them on the telephone. This is a way of protecting everyone so that they don't have to come out or go on public transportation or somehow expose themselves. As I said, there are also a lot of very careful precautions within the hospital and the medical center itself to separate out people who have symptoms and may possibly have Coronavirus infection from the rest of the people who need to come to the hospital for healthcare.

Dr. Carly Tanner:

So that's also happening, but for people who are just needing routine care for their Parkinson's, we're doing that all remotely right now. I will say that this is one of the areas I've been working in in a research capacity for a number of years already even before Coronavirus. We feel this is a really good way to provide care to people with Parkinson's disease because it minimizes the burdens of having to come into the hospital and see the doctor which can sometimes be a whole day of your time and someone else's time to come with you. So it's not a complete change. It's just the we've converted our entire clinic to telemedicine as opposed to some of our visits.

Maggie Kuhl:

And for people with Parkinson's even beyond this time, mobility is an issue so perhaps telemedicine will continue to be more widely accepted. In essence of time, I do want to move us forward and talk a little bit about other adaptations. We obviously just went into telemedicine and we've touched on some of these about referencing your doctor and your local and state health departments and national government organizations for the most useful and up-to-date sources of information. We've talked about checking with your insurance company or your government insurer and your local pharmacy about any changes there.

Maggie Kuhl:

I really want to focus now on caregiving and in-home care. A lot of people with Parkinson's rely on others for assistance whether it's someone in their family or a loved one or perhaps a home health aide. People with Parkinson's may be living in assisted living facilities, and it's just not always possible to really maintain a six-foot distance from someone when you do need that level of care. Dr. Leiber, what are you telling people about foregoing or adapting their health aides and care in this time?

Dr. Katie Leaver:

Yeah. So I think it's really a case-by-case conversation and thought process. Overall, you have to think about risk mitigation and there's going to be trade-offs between potential exposure and then real needs for continued help to maintain quality of life and ability. So certainly having that conversation with your home health aide, asking them about their exposure risk, what they're doing to practice good hand hygiene, and then thinking about what are my needs, but at the same time being realistic about if you do need to have this kind of care, you need it. So we are working with patients on a case-by-case basis.

Maggie Kuhl:

Dr. Erinoff, what about people in assisted living facilities who perhaps don't have as much power over their own environment or visitors? What would you tell someone in an assisted living facility or the loved one of someone who wants to look out for their family member?

Dr. David Aronoff:

Yeah, this is a really big challenge. I think as family members or patients at assisted living facilities, it's important to have conversations with the management of those facilities and get a transparent understanding of how they're dealing with this pandemic. So for example, what are their policies and procedures for sending people home who have symptoms or have a known exposure to someone with COVID or themselves are diagnosed? Most facilities should have by now guidance and procedures for how they're handling that. In addition, it's going to be important to make sure that at the entrance to these facilities that they're limiting visitors if possible to those who are essential for patient care or essential for the mental health or wellbeing of the loved one and that there's plans for how families can come and visit.

Dr. David Aronoff:

This may be a challenging time where young children are excluded from visits. I think you're going to see that that's a facility-by-facility type of decision, but I think we should expect that facilities will have some guidance around who can visit, when they can visit. It'll also be important to make sure that there are proper ways for patients, family members, and care providers to engage in hand hygiene. So whether there are sinks with good soap available for people which hopefully there are and/or good hand sanitizer

Dr. David Aronoff:

... Which hopefully there are and/or good hand sanitizer to be used as well. And that personal protective equipment like masks for example, are available when needed and when needed is going to be based on the infection control and infection prevention policies and procedures at each facility. But I think right now is a good time to have some conversations with the management at those facilities so that families feel comfortable that things are as under control as they can be, in an environment where we're all feeling like the definition of under control is changing every day.

Maggie Kuhl:

Yes. And we spoke when we were preparing this about that balance between isolation and the effects of that on Parkinson's and health and well being and that protection from the virus. And so Dr. Tanner, wanted to turn to you for these last two points that we see on the screen about about keep moving, keep an exercise routine. And we tell people with Parkinson's that exercise is often as important as your medication, but with so many classes canceled and gyms closed, how can people maintain that? That physical exercise. Do they really have to stay in their home or can they go for a walk on their own? And then also the social isolation, the lack of socialization with others. And if you are not able to visit loved ones, what do you recommend for staying connected? So any thoughts on those two?

Dr. Carly Tanner:

Yeah, so obviously maybe, especially now maintaining your physical activity and maintaining connectedness with people is really important. Even if it can't be a physical touching kind of connectedness. So people can workout at home, as you said, you can do a lot, there are a lot of different exercise programs that people can do independently. There may be classes that you can identify that are online that you can be involved in video classes. Some physical therapists even can go online and do a telemedicine assessment. So those are all important. Even here in the Bay area where we're told to shelter in place, walking outside with six feet distance between you and other people is something that is encouraged. And so getting sunshine, getting fresh air, getting out of your home and moving around, I think is critically important now. And will also help to relieve some of the worries and fears and anxieties that are just almost inevitable given the current situation.

Dr. Carly Tanner:

The other thing is being able to maybe even have more, being more proactive to reach out to friends, to reach out to family too. Have video chats or FaceTime or Skype so that you can actually see people even if you can't be necessarily with them all the time. Would be really important and trying to maybe schedule a little bit more than you would have at another point in your life to be able to be sure that you're connected.

Maggie Kuhl:

Yes, it is nice that we have so much technology to allow us to be together apart and I wanted to share with the audience that we are looking for your ideas and suggestions as well. We could probably have built the hour on adaptations and different ways that people are maintaining connectivity, connectedness. So starting next Tuesday on our social channels, on our Facebook, Instagram, Twitter. We're going to be looking for ideas with the hashtags together at home Tuesdays and sharing your ideas more broadly with our community so if you have found something inventive to stay connected or stay moving at this time, we're hoping that you are going to be sharing that with us over the coming weeks while we're all facing this together.

Maggie Kuhl:

I did want to touch on one more topic before we turn to your questions, and that is how this time and this period of a pause on a lot of our regularly scheduled programming will impact research. We are the Michael J. Fox Foundation for Parkinson's Research and we're concerned with the efforts toward a cure and new treatments for people living with Parkinson's disease. We know that research is going to take longer to begin and complete, but we are doing everything that we can to move things as quickly as is possible from our end. Understanding that a lot of the research is happening at academic medical

centers who are devoting resources to care for people with this virus and develop new treatments or companies who are looking out for their own employees. So Dr. Leaver, why don't you tell us at Mount Sinai how research has been impacted and what adaptations or postponements you all are pursuing?

Dr. Katie Leaver:

Yeah, so we here at Mount Sinai are trying to utilize the telemedicine option just like we are with our clinical visit for the research component. There's still a way to move a lot of the research forward through the telephone or video visits. And then with some of the interventional trials, this is again a day-by-day decision, but on a limited basis we are still seeing some patients for research that is an interventional type trial where we need to see blood. But it probably varies drastically by institution.

Maggie Kuhl:

So make sure that you're checking with your study coordinator if you do have an appointment scheduled or if you're just interested in the status of a particular study or trial that you've been participating in. Dr. Tanner, you are the principal investigator for our online study, Fox Insight. Why don't you talk a little bit about why it's still important for people to be contributing to Parkinson's research and how Fox Insight can help people do that from their own homes.

Dr. Carly Tanner:

Yeah, so this is a wonderful opportunity for people who aren't in Fox Insight to become involved with Fox Insight. And the website is right there and this is a way to understand more about people with Parkinson's disease. It's already set up to be what we call completely remote assessment. So there are kind of two aspects to it. One is the longitudinal collection of information so we can understand the experience of a person with Parkinson's but also people who are connected to people with Parkinson's, or people who just simply want to be supportive and aren't personally that involved with Parkinson's. So pretty much anyone can come onto Fox Insight and we're very interested in knowing not just how you are today, but in knowing that over time so we can learn more about Parkinson's disease. And we're also often focusing in on specific questions.

Dr. Carly Tanner:

So for example, there was a survey that tried to understand more about how Parkinson's disease affects the economics of health care and that's something that will soon be coming out in publication, but I was able to take into account not just the sort of cash that's spent in the hospital but also the broader experience of what we call indirect cost. So the cost of people at home and of people living with people with Parkinson's who may have to give up work time or pay for care partners. So I think there's many, many things that people can do that will help us understand more about Parkinson's and it doesn't require going out at all.

Maggie Kuhl:

Great. And if people are interested in joining [inaudible 00:50:24] if they are not already, it is also linked in the resource list that you see on your screen. And as Dr. Tanner said the URL is there on your screen now. So Fox insight.org. I want to spend the last couple minutes answering some questions. I apologize if our staff or panelists have not gotten to your question. We had many, many people join us and we do get to as many as we can. But some that has come through that I think the audience might benefit from hearing the answers to. Dr. [Aronoff 00:00:50:54], is there anything someone can do to boost their

immune system to help prevent contracting the virus? Something like taking probiotics or different vitamins?

Dr. David Aronoff:

Yeah. Boy, that's a really hot area and we're all eager to know the answer to that question. Right now we don't have a good answer that's specific for this virus. Our hope is that within the next 12 to 18 months we'll have a specific vaccine which will certainly boost our immunity against specifically this virus. But to our knowledge right now, taking any kind of vitamin supplements or probiotics may just have theoretical benefit, but nothing that's really been definitive or shown. And a lot of people are trying to start studies to look at that very issue. So it's certainly important and I wish I had a better answer.

Maggie Kuhl:

Okay, so stay tuned. We'll share more if there are any definitive answers in that arena. Dr. Leaver, a question on if someone is a caregiver or a loved one of someone with cognitive impairment or dementia, any tips for explaining what's going on in the nation? If they're seeing the news or if their usual routine, their visitors, their appointments are not as scheduled or as they regularly expect it. What can you be telling someone with with cognitive issues?

Dr. Katie Leaver:

I think with these patients it's important to speak in simple language as usual, but to give some reassurance that you are still there for them. Because they really, we'll probably notice this complete disruption in their regular routine. So as much as you can shift that routine into something new and do a daily or consistent reorientation or repeating that this is what's happening. Those can be helpful to just reorient people who might have some cognitive impairment.

Maggie Kuhl:

And Dr. Tanner, a question on breathing and swallowing problems. As reference, people with Parkinson's can experience those and the coronavirus is a respiratory affecting condition. Any thoughts on if it would worsen on those symptoms or if those symptoms would be particularly prominent in people with PD if they did develop the virus?

Dr. Carly Tanner:

Sorry, you were a little bit vague on a very big getting part of it. So we're you saying swallowing problems?

Maggie Kuhl:

Yeah, I think people are just saying that because this is a respiratory condition, the coronavirus and because respiratory issues can also come with Parkinson's, that is swallowing or breathing problems. Is there some sort of exacerbation of those or could people expect to see those symptoms more frequently in the Parkinson's population if they do develop the virus?

Dr. Carly Tanner:

Yeah. So I think what Dr. David Aronoff said before, a new problem would be something to be of concern. People who have these problems because this is part of their constellation of symptoms from

Parkinson's disease. I don't think we have any reason to think they would be more vulnerable to coronavirus per se. But if you already have a problem with swallowing or breathing or if you have some kind of respiratory problem, you probably want to be particularly careful, if you then develop coronavirus. Hoping that people don't develop it. Dr. David Aronoff, do you have any additional comments or not?

Dr. David Aronoff:

No, that's spot on. I totally agree.

Maggie Kuhl:

And Dr. Tanner, one more for you. Some people with deep brain stimulation who were either planning to have the procedure or who perhaps have already had it and need to go in for programming. What is the recommendation on either continuing to pursue that treatment or having those doctor's appointments to help with that treatment, DBS.

Dr. Carly Tanner:

Yeah, so that's again a sort of case-by-case and hospital- by-hospital situation in our hospitals. The surgical service is certainly in touch with everybody and people who have urgent needs. Like people who need a battery replacement, something like that can be treated. People who are say on the list for a surgery, maybe that will be postponed for our period of time. But again, every part of the country is different, we're kind of the, sort of the maximum, I guess epidemic phase at this point. So that's what's happening here. I think that what is true is that your own hospital, your own medical center, your own surgeons and neurologists will be making plans that are appropriate with the condition where you are. And they will work with you to make sure that you get the care that you need but in the safest way possible.

Maggie Kuhl:

Okay, and one last question, Dr. David Aronoff. I think a lot of people are wondering when will we know it's safe to resume perhaps new normal version of life. But say you want to visit your grandkids and you've self quarantined for two weeks and you don't have any symptoms. Is that long enough or should we be waiting for the government to lift the ban on of these restrictions? How are we going to know when we can go back to the way things were?

Dr. David Aronoff:

Well, I think that the answer's going to be different in different regions as we've heard a little bit today. But I would really emphasize that it's important to listen to our local departments of health to tell us when the all clear has been made. Your example is a really good one. I may be in my home for two weeks and feel perfectly good and then want to go and visit young children who themselves may feel perfectly good. But until we know that the epidemic is under control in that area, that other party, the little kids, they might be shedding virus. We just can't tell very well in these days where the virus is still in our community, who might be contagious and who is not. So it's going to be an estimate but I would really look to our local health care public health sector to say businesses... When we start hearing businesses can reopen, restaurants can reopen.

Dr. David Aronoff:

We no longer have 50% capacity rules. These kinds of things are going to be the way that we understand that the lid is coming off and we can come out of our little holes and start to act whatever that new normal is again. And if there's any questions, I think it's perfectly reasonable to call the Department of Health. They probably, most places, have a coronavirus hotline, which right now is probably pretty busy with all sorts of questions about should I be tested. But at some point when the activity is, in the area is going down, it's reasonable to call those numbers and say, "Hey, do we have the all clear?" If you're not hearing it in the news.

Maggie Kuhl:

A lot of unknowns, but a lot of people working to get answers as quickly as possible. I want to give all of the panelists an opportunity to leave some parting words. We've covered a lot in the last hour. Again, I'm so grateful for your time and expertise. I know people are wondering about a lot that we were not able to get to. But perhaps we could just go through and you could each share a sentiment or a takeaway that you hope that the audience is leaving our call today with. So Ted, why don't I start with you.

Ted Thompson:

Thank you. I guess my parting comment would be to try not to panic and try not to get wrapped up in the hysteria. That seems to be pretty pervasive out there. We at the foundation from a public policy standpoint are doing everything we can to assess what's going on and to be helpful, from a policymaking standpoint. But basically just ride this out and try to focus only on reputable news sources, for example.

Maggie Kuhl:

Dr. Leaver, any comments for our audience?

Dr. Katie Leaver:

I think that I just want to let people know that, you know, us physicians are still very available for them through the phone and telemedicine. My hope is that some silver lining that comes out of this is a jumpstart moving forward with different types of availability for people who have mobility issues. And it's really, I think going to change a lot in some for the good. So that's something we can have hope for.

Maggie Kuhl:

Okay. And Dr. Tanner?

Dr. Carly Tanner:

Yes, I echo what Ted and Dr. Leaver said too. I think that being calm, recognizing that there is help available. That it will come from... You can reach out to community services. You can also reach out to your physicians, healthcare professionals. And that there are a lot of services being mobilized to help people who aren't able to get out or to get around. And I think as a community together, we're going to get through this.

Maggie Kuhl:

And Dr. David Aronoff, last word is yours.

Dr. David Aronoff:



Thank you so much. I 100% endorse everything the three other panelists just said. So I'll just close by saying that it's an absolute honor to be able to be a participant in this panel with such wonderful co-panelists. And I think the work of the Michael J. Fox Foundation to help inform the community is really vital and much appreciated.

Maggie Kuhl:

Great. Thank you and as Dr. Tanner said, we're really all community and to our panelists today, thank you for your time and expertise. To everyone who joined us, I hope you found it beneficial and supportive during this time. Please look for more information on social channels, our website. Please share what you are doing during this time, what you're finding helpful over the next couple of weeks and just, yeah, have a great day. Again, wash your hands.

Dr. David Aronoff:

Right.

Maggie Kuhl:

Thank you.