

The Invisible Patients

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Sometimes I feel like it's kind of third world medicine in a way like going out to the field, you don't have every single thing you need and you do the best for that person that you possibly can. I think; and I think that's okay. Because frankly, if I wasn't doing it, a lot of these people would get no care and they would just show up at the ER in a total mess.

This is for you and that's for your bear. I am not going to give your bear real juice.

It would get dirty and smelly and Ewww.

No, he just pretended to drink juice.

[unintelligible] 8 minutes.

I know.

5 [unintelligible].

Hi Roger.

Hi

How are you?

Alright.

What's going on?

Just a little pain. I guess.

Where's your pain today?

Back.

Your back?

Is it kidney stone pain on the left?

Yeah.

Yeah. Because I got that ultrasound back, I just got those ultrasound results today and there's quite a few kidney stones in the left.

Roger Brown is a 30-year-old man with Duchenne's muscular dystrophy. He was diagnosed when he was 4 years old, and I think by the time he was 6 or 7, he was in a wheelchair. He was able to go to the prom in a wheelchair with his girlfriend.

I don't know if you would know much about Duchenne's muscular dystrophy but it's a progressive muscle disease. It deteriorates the muscle until there's nothing left and then it starts on his internal

organs. Right now, he needs a respirator but Medicaid don't want to pay for it, unless he goes in a nursing home for 30 days.

How's your breathing been?

It's been good.

It's been good. It's really the pain that's getting me down. Right now his heart is in heart failure because it's a muscle and it's not working anymore. His ejection fraction is at about 20%, so fluid builds up in his abdomen and in his extremities.

I would like you to increase that lasix to 2 and 2. We've got a delicate balance here, because he needs fluids for the kidney stones but his heart can't take too much fluid.

That sucks.

It does suck.

We had a really wonderful and sad conversation last week about end of life care, what he'd like, and he told me I want to do what I have to do, to live, to live as long as I can, I want to prolong my life as long as I can until I tell you that I don't. And when the pain is too much and when my breathing; I am struggling too much, I will let you know, but I want to live for as long as I can. And I think that's completely reasonable for a 30-year-old person.

Try the extra pain medicine, a little bit of it okay. Try it. I know you don't like pain medicine. I think you are the only 30-year-old who doesn't.

I mean the average length of time that someone's on this kind of service is two years. So, you know I am going to watch or be with families as they transition into something else, whether that's death or nursing home or whatever. And I would say, I mean on the average at least one of my patients is dying a week. And if you, if I let myself go there every time I won't be able to do this very long.

Today, I am here to see Pat and Wink Sherrill, a married couple, they have lived in this apartment for I think 27 years.

I ain't been camping in my life and I don't want to go. Not in our woods. I would be afraid of snakes, spiders and everything else.

I was born and raised in Kentucky; Campbellsville, Kentucky. And I stayed down there till I was about 18 years old. I worked on a farm. My dad had a farm. I left from there and I come to Evansville here and I have been here ever since. I retired as a carpenter here, 40 years.

I was born here but I have been raised all over the country because my step-father was in the service. Only place we didn't get to go was Hawaii, because he died with open heart surgery.

They had been going to the same doctor for a few years. They felt comfortable there.

Well, the thing of it was. We were going to this doctor and man he pulled a thing on us.

He put a red flag on us.

He got in a bunch of trouble over doing a lot of people dirty.

They both take prescription narcotics for arthritis pain and there are new laws in place where if someone takes prescription narcotics, they are required to take a drug screen at least once a year to make sure they are not using any illicit substances. Number two, to make sure that what they say they are taking is actually in their system, because of course diversion or selling narcotics is a growing problem. The street price of a narcotic, one pill is like 10 dollars.

Patricia took her drug screen and it came back negative for her narcotic that she was supposed to be taking, and that's a problem. At that point he kind of justifiably discharged her from the practice.

One day he called me up, when I had an appointment down there, just called us up and said, well I don't want to see you anymore.

But in their words, they felt like they got blackballed. When they tried to get another clinician, a physician, a nurse practitioner in town they got declined.

And he went and put on all of the computers. Put a red tag on all the people he didn't want to see.

I couldn't get a doctor in this town for both of us.

A red tag so no other doctor would see us.

Through St. Mary's or Deaconess or anything.

So, they were unable to find someone to take care of them for about 8 or 10 months which was a huge problem because they have chronic health problems. But I don't feel like as a community we can just discharge people without care and then have nobody to accept them back into their practicing. Somebody's got to take care of them.

You see I was so clogged up.

You were clogged up.

Right here.

And so, that was to get it;

That was the only problem I had by the colon but he said everything up here was just fine.

Fine. Did you do that miralax cleanse that he recommended?

Yeah.

That's even worse, isn't it?

Yeah. I don't want no more of that either.

Okay. So, you are cleaned, I mean you are clean.

I am cleaned out.

So, what I would recommend that you do is take a break from that pill.

Yeah, I am.

And then even take a break tomorrow, and then start with one every other day.

Okay.

Did he give you samples of it?

Yeah. My insurance was paperwork.

Right. It's expensive medicine.

Yeah, for 30 of them, 275 dollars, no I don't think so.

The issue is going on with Wink that he just had a prostatectomy, a prostate surgery for prostate cancer. And then he's got all the run on the mill chronic conditions that men who are in their 70s tend to have, high blood pressure, high cholesterol, arthritis.

8-10 years ago, Crohn's disease hit me. And then I had to have a surgery done over that and I had to have my lower colon part of it removed. Upper colon removed, part of it. And a Tumor took out of my stomach. Just a little bit of everything. It just put me down, I had to retire.

All right, Popa Wink what's going on with you?

Well first thing is I got a sore stomach.

Yeah. I am going to press a little bit okay.

Okay.

I am going to start way up here.

Okay.

Are you hurting there at all?

No.

I am coming over here. How about up in there?

Just a little sore right there.

Little sore there. Can I see your tummy, just the skin? We probably won't have to;

Yeah, sure.

Okay.

You can see where he's been cut.

But you don't think it's your colon. You think it's from the surgery.

Well, I don't know. It could be my colon too.

And I had cancer on that.

Whatchamacallit they took out, they got rid of all of it.

Got rid of all the prostate cancer.

Yeah.

Did you have bladder stones?

Yeah.

Yeah.

Okay.

Yeah, he went in my bladder and took it out of my bladder.

Okay.

But they went up the other way.

Right.

Well, I am so sorry that it's been such a hard recovery.

Well I know it.

Yeah.

And you all are such good people.

Well, you are a good person. It's easy to be good to you.

You have, you all have been so good and nice to us, we don't know how to thank you.

Well, you don't; that's my job.

I know.

And I enjoy it.

I know.

I am not naïve. I know anyone is capable of anything but I am just keeping a close eye on it. I don't believe that they abuse their pain medicines. I don't believe they sell them. I believe they both need them.

You think you are getting a little depressed?

I might be.

I think so.

Did you know that when you have depression, that your pain is worse?

Yeah.

Everything is worse.

I am sorry about this.

That's okay. I am so glad I am here today because oh my gosh I didn't know.

I sit here and I worry a lot about things I should not;

You're worrying.

Yeah.

Okay.

Oh boy! Yeah! Sometimes you come and you have one complaint. You think that's the problem and that's healing, that's not the problem today. Your spirits are the problem.

Yeah.

Yeah. Okay. Good thing is we can work on that.

But I don't give up.

No, you don't.

Well he don't give up.

No.

Yeah, too strong to give up.

There you go.

Yeah, okay. I am going to come back in two weeks.

Okay.

To check on you both okay. But I will make sure to get your medicines called in when they are due.

Okay.

But you are going to get something for your nerves okay.

Okay.

Yeah.

And his depression too?

Oh yeah. Yeah.

Get something for both.

Oh yeah.

I sure appreciate it.

Yeah.

Pinball?

No, it's a nerve right. Can I have a hug before you guys got to go?

Okay, thanks.

I will give you a hug. Where are you going today?

Evansville, Newburgh.

Good. How many?

10.

I did have another person on today but I always read the obituaries and I open the paper and someone I was supposed to see today passed away on hospice care. So, it was expected but she passed away on Saturday and I am a little irritated at hospice because they didn't let me know. And then you know you feel like an idiot when you show up at the house and no one has told you that they passed away. I prefer

to see 8 patients a day. That is my comfort level. Doesn't sound like a lot because when I was in an office I saw between 20 and 25 but a lot of those were really quick strep throat or skin infection or something straightforward. All of these patients have multiple complex things going on.

If your breathing gets to the point that you need a ventilator, then the three of us will have to talk about whether you want to go to the hospital or not, because that's the only way they are going to pay for it. My feeling is to think on it and cross that bridge when you come to it.

When do you think it will happen?

So, hard to say. Right now your breathing is stable, and I do want to be real honest with you. I don't have your echo yet but of course with muscular dystrophy your heart is going to continue to; that muscle will continue weakening and not pump as well. So, at that point I am not sure there's going to be delicate balance of what happens first. If your heart really gets sick, there's not a lot of sense, commonsense putting you on a ventilator because that wouldn't keep your heart going. It would do the breathing for you but it wouldn't keep the heart pumping. So as all of this unfolds and plays out over time, I feel like the ventilator is less of an issue right now. Right now, it's your heart and taking the fluid off you so that it pumps adequately.

Is there any way that it might get a little bit better after the fluid gets off? I know.

Your heart won't get better. We are taking the fluid off. No. You will feel better because the fluid will be off, but it's not going to make the muscle any better. Which brings up my next thing I want to talk to you about, Medicaid, I might be able to find a Medicaid hospice service. I was talking to a case worker about that.

Once you get a person on hospice, it's this huge relief, you don't have to do things you don't want to anymore. You don't have to take medicines that give you bad side effects. You don't have to you know go to the hospital and hospitals, they serve a purpose of course. I am not anti-hospital but patients don't sleep, they don't eat well, they are exposed to infections. I try not to push but I want people to know that they can spend the last few months of their lives or weeks of their lives not doing unnecessary stuff and just spend it with the ones you love. You know keep your energy for that. So, that I wish we would have more honest conversations, with people about; it's a really hard thing to do.

I don't want to talk you into it either way but I think hospice might be a good thing at the moment. And then, we just have to take everything as it comes, every symptom we have to manage and then make a decision at that point, you know, how are we going to manage this one, how are we going to manage this one.

Do you think he will end up in a nursing home?

Unless I die, I know he's not going away.

This is where he wants to be?

Yeah.

I think today when I told him his heart is not going to get any better with medicines, it's just going to make him feel a bit more comfortable, I think that might help them towards this decision that you know

we are coming to the last chapter of his life, I don't want to give a timeframe because I don't know, nobody knows. I think it's best just to keep him comfortable in a home where he wants to be, and I think if I can find a hospice that medic that will take Medicaid that's an issue as a lot of hospices or any agency for that matter won't take Medicaid as an insurance. So, finding that agency to do that will be a challenge. And I have one in mine that I really want to take care of them. So, we will see how he does next week.

Hey Ron. Good afternoon.

Good afternoon.

Nice to see you. How are you doing?

Jessica

Long time no see. You got a good one. Mine like a steel trap.

It's been shook around;

It's been shook around yeah.

Too much.

I always think he's younger than he really is. He's in his early 60s. I think he's 63. And I think when I started seeing him he hadn't been into an office a few years.

His brother is an interesting character who hopefully we will meet sometime.

But you do pretty well, don't you?

I have so much more to do.

So much more to do.

Yes.

You will see in the house there's a wooden chair that he made, so he wasn't so much a painter or that sort of artist, but I think he worked with like 3D, like ceramics and woodworking and sculpting.

He went to California and got in a motorcycle accident.

Health wise, what's going on with you? Are you steady as a rock? Any complaints or concerns?

I think I need to do something to make my muscles, more muscular.

Have you; when was the last time you've done any kind of physical therapy?

I don't know.

Been a long time okay. Now, if you are talking about your muscles, which you want more upper body strength or lower?

I think I need to talk to mister balance.

Better balance.

Any!

And I will look into getting some therapy for you here in the home to see if we can get you a little bit stronger and more mobile and balance. And that's going to be tough. You know with a brain injury there's going to be limits to what they can do but surely, they can make you little bit better. Sound like a plan.

Super!

Okay. And I will be back next month to check on you.

Oh, my god!

And it's not time for lab work yet, your lab work was all fine. Even your cholesterol was good. All right. See you next month. Thanks.

Too long. Too long.

Okay. Keep up the good work okay. I will see you next time. Bye sweetheart.

The good work? Ha!

When you're a nurse practitioner and you are not in a traditional office. This is the line people always ask me now. What doctor do you work under? I don't know why that irritates me but it does. I have a collaborator, I have someone who helps me in sticky situations, but I don't work under anybody's; there's this perception that you are kind of just like a little minion that's carrying out activities for a doctor. I hate the hierarchical stuff. I know that's just, I just do. I hate the term physician extender. I hate the term midlevel provider. I don't feel like what I do is middle of the road care. I feel like it's really good care. I want to be called a nurse practitioner. But I do think that care happens best in the team, and I feel like what I am doing right now works really well, because I have a really, really good collaborator who is very willing to; he never sees the patients but he listens to my clinical case. I tell him about it and I tell him what I think I am going to do, and then he makes suggestions and I trust him 100%. And I think that's a good model and I think that's where if we want healthcare for our whole nation, we are going to have to rely on some nurse practitioners.

This week he has been thinking about death a lot. And I have tried to assure him that you are not going anywhere right now, but I guess if I was in his position I would be panicked too. When you have the DNR, they are talking about Do Not Resuscitate and have you made the funeral arrangements yet when I go; hang on a minute, we are not that far.

Hey, how are you? Thank you.

All right.

Hi Scrappy.

All right. Do you have you know spiritual or religious beliefs, convictions?

I do, but they don't go very far. I am not like completely, you know, into all of it. I respect some of it, but not all of it.

Some of it.

We are just so scared of dying and so we are not honest with families about their lifespan or their loved ones or the patient. We are not honest with them that you don't have very much longer to live and that what we have available to you, we can do a bunch of stuff, but it's not necessarily going to change your outcome or prolong your life.

Let me put it to you this way, I should have funeral arrangements made. You should.

I should, yeah.

Everybody should because you are chronic; I mean nobody knows what's going to happen day to day. And so, I think hospice kind of pushes you to make it a priority to think about those issues;

Well I'll tell you this.

Tell me this.

If my heart goes out, I don't want to be resuscitated.

Okay.

But if my lungs go out I want to be resuscitated.

Okay. You shouldn't be having this conversation at age 30, but we got to have it. You know that your heart is sick.

Yeah.

Because of the muscular dystrophy and that it doesn't pump well. If your heart gets sicker, what I would recommend would be to not resuscitate in any form. Because there's nothing that can make that heart well again.

I usually talk to him about death and the DNR and things like that, but I am basically waiting for him to make a decision on what he wants to do. I am not going to push him into [unintelligible].

Do you think Roger has a very good sense of what is going to happen to him?

Yeah. I think he does. But he's also told me many a times that he doesn't want me to worry, he doesn't want me to cry, he doesn't want me to be sad. He actually told us to have a party and turn on his favorite music and I don't know that we will do that but that's what he said.

Do you feel better?

I feel better because yesterday I went and got my shot.

Your labs are great. You look good, you are picking up a little weight, all right. Let's go to Wink. How are you doing?

Well a whole lot better.

Better?

Yeah.

Are you taking that pill for nervousness and depression?

Yeah, is that for both.

It treats both.

[Unintelligible]

Yeah.

I told Patty it probably was. You know everything looks a little brighter.

That's good to hear.

And I mean my mind, you know, working on things.

Yeah.

Getting a lot of this here bad studying off my mind.

And I am glad to see you smiling this time.

Thank you.

Oh! you're welcome.

And the good Lord up above up there.

Yeah.

I don't leave him out for nothing.

No. No.

I was able to get Roger on hospice services. That has been fantastic.

They come in and they help me give Roger a bath and Mia, the nurse comes and evaluates everything, his skin and his medications and his food and they are just all around good people.

He's kind of flirting with the hospice nurses in a good way.

[Unintelligible]

How's your spirit? You are still sassy?

Yeah. A little sassier.

You are obsessed here.

I feel like my spirits are high. I have a lot of hope. I have got a lot of strength. And I want to live.

Gentleman didn't have his pants on. First go around.

I work so many more hours now than I ever did. And these patients are truly my patients that I am responsible for them and I do worry about these people. There's couple I want to, couple I called yesterday on my day off because I worry about them. And that might; I don't think it's just me, I think a lot of them [Unintelligible] nurse practitioners feel like they are never off. I think it's a common feeling and I don't know how to handle that better or I would like to find and [Unintelligible] handles it better and talk to him or her.

What I really want to happen is I want a magic fairy to do my grocery shopping tomorrow and plan all the meals for the week.

Hello.

Hello.

How are you doing Louie?

I am dead.

You are dead.

Yeah. This is normal.

I have never heard someone speak from the grave.

And now you have.

I am glad to see you.

I bet.

Tell me about your relationship with your brother Louie.

He's recovering from a heart attack and I try not to hassle him, but he is Louie.

Good morning. Are you still half asleep?

Yeah.

I hear you got something going on with your toenails. They are not terrible but they don't like you doing them yourself. You have a clipper?

Yeah. Somewhere.

Because I am happy to cut them, I just need a clipper. Do you ever get out of the house like to see a foot doctor?

No.

They are not too bad though, believe me, I have seen nails that haven't been clipped in years. Look at that. You are ready to model your sandals. You have one refill, a 90-day one on that. And then another 90-day on that. So, we are good for another about four months.

Okay.

Okay, all right, I will see you next month.

Bye.

Keep up the good work with your therapy and the stretching part. Look at you.

I try.

I know you do. I am glad to see you. I will see you next month okay.

I can't wait.

Okay. Thanks Ron. Talk to you next month.

Okay.

Alrighty. Bye Louie.

Do you do refills on medicines?

For patients that are enrolled.

Oh, I am going to die anyway.

His feeding tube is acting really strange. It used to be really tight up against the stomach, and then for some reason it's lifted like two inches. This morning all of his medicine came out, so he probably didn't get much of it.

That's really sore. So, here's what I am worried about which is going to take precedence over all the other issues. I mean you are not acutely ill you know but I am worried that the leaking maybe his caused what's called peritonitis or an infection.

So, I did okay, giving you that.

You didn't do; it might have helped his pain, it didn't hurt anything.

A lot of what we decide to do is going to depend on what you are willing to do.

I can't guarantee that you are not going to get really sick.

Like what are we talking about?

Well, like overwhelming infection. So, the most cautious thing to do is to send you in. If there is infection you would get IV antibiotics.

In that [Unintelligible] in hospital for you.

A while.

I know you are on hospice and I know you are not interested in doing huge amounts of things to prolong your disease course. But I don't know if you are willing to risk letting this feeding tube malfunction you know be something that ultimately could take your life.

I am not staying home if it's going to kill me. I gotta leave.

Do you mind if I step outside and make a phone call to Dr. Jacksons and I want him to completely understand before we make this huge decision.

The problem is that the ride in the ambulance is so traumatic for his breathing, partially to his anxiety and partially it's just he can't breathe when all those factors don't line up for him, when his fan is not on him, when he's not on his particular BiPAP. He has to be in that one position to breathe.

Hello, I just; I need your advice on this one. He just had some water and it's coming right out. His belly is pretty tender everywhere, and he's afebrile, but I am just worried that he's got some infection now going on. Is that reasonable to think? It's really loose, I mean I can; I am not going to tug on it too hard but I mean I can move it inches in and out. It's not sutured down anymore. His respiratory status is just so precarious that going in really shakes him up.

I don't have a choice?

Not really, not right now, no. If his heart was a little sicker, he would have a choice. But it's not.

I don't know what to do? I don't know whether to go to ST. Mary's or Deaconess. I hate Deaconess. And the last time we went there they ask me if I pulled his feeding tube out.

Oh, you are kidding me.

Are you crazy. And then the doctor knew what happened. I said no, I didn't.

I think a lot of these people get judged when they go to get their medical care, there is a judgment call made about who they are and I think care definitely suffers according to who the provider, whether it's a nurse practitioner, doctor, thinks the patient is. You know if they think they are a good person, and they are educated, they get one type of care and if they think they are poor and you know maybe have had some trouble with the law, they get a different kind of care.

I don't think I did anything.

Of course, you didn't Shirley. Goodness me, is that what you are worrying about?

I just did what they told me to do.

You did nothing. You absolutely did nothing.

But I want to know. I want them to give me a full report of why. Why it happened because that doctor needs to be sued because Roger told him it wasn't right. He didn't listen. I am not right. They ain't no use in crying. Let's just do it and go do it and get it done.

Do it and get it done and come home.

Maybe I am completely wrong and maybe they will CT scan him and change the tube and that will be it. It's hard to know what's going to happen. I mean that would be a best-case scenario and you get your tube changed and you would be on your merry way. So, I think we just have to take it step by step. I don't think. we just can't know until;

They do.

They look at that tube and either pull it and put a new one or do a CAT scan and see.

Hi, this is Jess McCloud. I am a nurse practitioner with a home care patient. My patient Roger Brown has a feeding tube that's come loose and he is stable but he needs transport to the ER.

He has infection and she don't want to treat it here.

If anything changes you just let me know okay.

Sure. Thank you for your help.

Thank you.

I think it went a little [Unintelligible] than last time.

Hi.

Hi Shirley.

Yeah.

It's Jess. I am just calling for an update. How are you this morning?

Alright, Well, last night they did that CAT scan and the urologist came a while ago and Roger has, she said both of his kidneys are full of kidney stones. And he has a 6mm one right how that's in his ureter.

Okay.

And he has a 6 mm lens right now that's in his [unintelligible].

Okay.

That we were waiting for him to pass.

Okay.

And the anesthesiologist came in and him and the urologist both think it's too risky to put him under.

Under okay.

To take the kidney stones out so they don't want to do it unless it's a life or death situation.

Okay.

And feeding tube, they put a temporary one in last night like I told you.

Yeah.

And the nurse put the medicine in there and all of just ran right back on his stomach.

Oh really?

Yeah.

So, we are still waiting for a GI doctor to come and tell us what to do.

What to do. So, but he's going to get to see a GI doctor.

Yeah.

Thank goodness, that's really what I wanted. Alrighty, well, sounds like he's in good hands. Give him my best.

Okay.

And keep me posted if you think of it, but I will probably call you tomorrow too.

Okay.

All right. I am glad it's getting taken care of.

Okay.

All right talk to you later.

All right.

All right. Bye.

Bye.

It's been kind of rough going through all this again. I have been getting a chaplain to come up here and they have been praying for me a lot. I used to not believe in prayer and all that but now ever since I got worse. I tend to believe more. I think it's just a sign from God that I am going to be all right as long as I try to believe that there is a higher power and that he does help, at least he tries.

Yeah, the feeding tube is good. We are just worried about the stones that he's got to pass. And so, we are going to go home and hospice can come back and we will start all over again.

Okay, so this morning I was asleep and at about 6 AM the phone rang and I saw it was Shirley's number and so I answered and she said Roger had really taken a turn for the worse overnight, a lot of shortness of breath, a lot of nausea and dry heaving, and they had had the hospice nurse out there who you know recommended some nausea medicine and some pain medicine but I could hear in her voice, she really wanted me to come, so I said, you know what, I will be there at, I just got dressed. And so, I got there and I mean it didn't; it's pretty clear, he's transitioning into death. And it's truly a process, I mean, it's the wildest thing to watch. It's a process of dying. Shirley knows it, she just needed me to say it. She said is he. And I said he is dying. And then she lost it. She absolutely lost it. She wailed; I mean she's shaking. And it was a little bit of a surprise to me because it was like she was completely unprepared for it emotionally you know like your kid had been hit by a car and you just found out. Shirley and I just talked for a good hour and a half and she told me Roger is her best friend and she doesn't know what she'll do without him. And she's just not ready for him; she's just not ready for him to die even though she was told you know he won't live to see 20 and he's 30, she's not ready.

So, what was happening is I was on the porch, Shirley was smoking because she, she's been up all night. And I would just go in every 5 or 10 minutes to check on Roger and make sure he was okay. I just put my hand on his chest to see if his chest was still rising and falling, and he opened his eyes, and he said I love you. He did and I said I love you too. And he said thank you. And I told him his mother was all right because I think that's a huge concern for him that she's going to be all right and that we were; she's going to be with him or right outside and then he went back to sleep. He's a pretty special guy.

So, what's next for you? Where are you going now?

So, for me, I had made a; I woke up at 6:00 and my daughter was mad at me because she said, you are not going to be back in time for my cello lesson. And I said I will, I promise. And I am not. So, I am going to meet her over her cello lesson and then we are going to go shopping for jeans and then I promised Shirley that I would go back this afternoon but I promised my family other things too, so I hope they understand.

Okay. Good luck.

Thanks.

Okay, so going back to see Roger. It's been about three or four hours since I have been there. Haven't heard from Shirley which is probably good. I just want to keep Roger comfortable, I want to keep Shirley calm. And just be there for them, that's all. Just want to keep checking in. Okay, I know where I am. It's a beautiful day. Family is there, that's good.

And it's okay if he doesn't feel like eating. If you don't want to do the tube feeds just back off.

I really felt this morning like anything could have happened. I mean I felt like you could have died.

That's what I felt like.

Is that what you felt like.

Yeah.

You are different now and it's so unpredictable, I feel right now like your body is getting tried. Do you feel that way?

And so, my goal and hospice's goal, what we want to do for you is to make sure that as you transition from this earth that you are comfortable and your symptoms are controlled and that you are not scared

I am.

Yeah.

Yeah. Not scared of that, just scared of leaving my family behind.

Yeah. I know your mom, she's going to be okay.

Yes. She's really, really strong.

She is. It's okay for you when you are ready to go ahead and let go. I am sure so many things are running through your head.

Because I do want to be woken back up.

What do you mean by that?

Like I guess resuscitated.

Resuscitating a heart that's functioning at 10% is not going to work.

I figured.

I wish it were so different.

I just don't want to do something that makes it even worse.

Yeah, and that would make it worse.

Yeah. I don't need anyone, anymore suffering.

You don't.

CPR works when you have a healthy heart to begin with and you have someone who is not chronically ill. If you have a sick heart, like he does because of the MD and his lungs the way they are, number one it's not going to work, it's not going to bring him back and it's going to hurt him. And two, if it did bring him back, he would not be anything close to the person. He would suffer so much brain injury that;

Yeah.

And I just; I don't want to be pessimistic but I want to be realistic because in my mind it would be a really kind of a cruel thing to do. You can't predict anything, just be together, be close and treat his symptoms. But he's good right now. You got a little break. Just a common changes and we will help you manage the symptoms okay. You need to eat, drink, and sleep too because you are growing a baby. All right, thanks Shirley, I will talk to you later.

Hi, sorry it's so late. Now, did I hear, are you losing your benefits? What's going on?

Yeah.

So, what's that; how's that going to affect you? What's;

I don't know. My sisters helping me to get through this, I don't even know if you all are doing this or not, but it's the health market plan, through Med-Wise.

Okay.

It's Obama Care thing. We didn't know if you all did Obama Care or not.

Yeah, what I am going to do is we have a social work department that knows all about the different insurances and that stuff. I am going to have them call you.

It's going to cost me a \$138 a month.

Okay. Because you are on Medicaid right now but they said you make too much.

Yeah, I have been.

But you don't have Medicare too?

No, not until I am 65.

Okay. I have a very nosey question to ask you and you don't have to tell me but I am actually curious what do they consider as too much income a month for Medicaid?

You got to make \$1305. That's their limit.

If you make over as a couple?

Yeah.

As a couple. 1300 a month.

If we make \$1305;

So, we made like \$400 and something over.

Do you think you are going to be able to get by with that extra 130 a month for insurance?

Well, we are hoping so.

I think we will make it all right.

I think we will make it okay.

Well, happy thanksgiving to you okay. I will see you next time okay.

All right.

Talk to you later. Bye Wink.

Bye.

Be good.

Don't know all eat too much turkey now.

I am going to eat a lot.

You all take care.

My daughter she piled a plate that high.

Then he does.

She always makes a big plate.

A big plate that lasts us for 3 or 4 days.

So not a whole lot new has gone on since he was so sick that Saturday.

He did eat a couple of bites of mashed potatoes and gravy.

Excellent. How did that taste? Really good.

Yeah.

Amazing.

He loved it.

Amazing.

It was amazing.

Yeah.

Good deal.

We all need to talk.

We all need to talk.

about something.

Okay.

that you brought up a long time ago. I need to talk to you about it. You know if I you know, die or whatever or pass out. I don't know if I want them to bring me back.

If you were to stop breathing you don't know if you want them to bring you back.

Because, I don't know what's going to happen.

Tell me what you are thinking.

I just think. It will put me in a lot of pain.

It will put you what?

In lot of pain.

You deserve me to just be really upfront and honest with you.

Yeah. I need that.

You need that. Your body is winding down.

Yeah, I know.

You know it yeah.

I know it. I know it's going to happen.

Yeah, you know to try to bring your heart back or try to bring your lungs back it wouldn't work, because of how sick your body has become with the muscular dystrophy. I want to be flippant and say it's natural but it is, we are all, we are all headed there. Our bodies are all headed there one day at a time. None of us knows when or how.

Yeah. I know.

Yeah.

I don't want it to happen at all.

You don't want it to happen at all.

But it's going to.

Yeah.

Its nothing. I can control.

It sucks. It's not just the breathing anymore, it's not just your respiratory functions, also the heart muscle too, the heart muscle is just sick. And so, the chances of you going on to a ventilator and getting better are really low. You would go on the ventilator and you would still pass away after all that. It's better to be at home. I hope I am not being too like judgy and telling you what to do.

No.

You tell me what you want to do but;

No. That's what I want. That's what I want to do.

Yeah. You need to pass away at home with the people that love you. Not in some cold hospital bed.

Yeah.

You are comfortable here. You got everybody you need. And the other thing is that when the time does come, you've got a team behind you who are going to be with you. We are not going to abandon you. We are going to help your mom. I think you need to know that she's going to be okay.

Yeah.

And you need to know that she's going to be okay and she's needs to know that you are going to be okay.

I should be okay.

I know. I know.

They say that up there is a magical place to be. It's Okay. I know. You are her baby. You first kid.

Roger's just an amazing person.

He's incredible. I mean I don't have words for it. I don't know that; you do either.

I do.

No, no, yeah, all right. [Unintelligible]. Would you call me?

Yes.

All right. I will talk to you later.

I barely really did a physical assessment. There's no; it's not about his physical health anymore in terms of there's no curing what's going on. So, it's all about his emotions now and whether he's comfortable and he is definitely declining. I felt like today was kind of poignant and sad because I feel like it's close. And what he said, I wish we could get that quote, he said it's like fighting a battle every day that you are never going to win. I can't even imagine what that must be like. So;

He can't cook, he can't boil water and my god they took his two meals a day and tore that down to one and now I got to feed him the other meal and what the hell? why do I have to do that? So, you know, they changed that part of the game and now I am supposed to cover his ass because he won't pull another penny out of his pocket because he is a tight ass. And I can either let him starve or feed him so you know;

You know better?

Was that a come in or don't come in?

You don't have to knock. You can walk through.

Nice.

I am in pain and can't do shit about anything.

I thought the physical therapist was going to get you a new wheelchair.

I was thinking that too.

I need to check on that. Well, have you had any concerns since last time, any coughs, colds, pains?

I've been healthy.

You've been healthy.

I believe so.

Good. Are you eating okay? Your appetite is as good as normal?

I hardly ever have enough to eat.

Okay. And when you say you never get enough to eat, do you just mean that you can eat and eat and eat, there's enough food. Is there enough food?

Yeah.

I am just trying to understand the meaning of that.

I just eat like cray.

Okay. Not fair, you stay so slim. You can eat whenever you want and still stay that slim.

That goes back to my training as an athlete.

An athlete. You are training as an athlete.

Yeah. Wrestler.

Wrestler? Were you pretty good? Did you win your events?

I did get a trophy for the most pins!

The most pins. Damn! Thank you.

Thank you.

See you next month. So sweet. Thank you. I will talk to you later.

Can I have a free pick in your brain?

A free what?

A free pick in your brain?

Sure.

He has somebody else that does his financial end and for some reason he called my dead brother's ex-wife because he is himself and the next thing I know is I am a third-rate citizen. You know, I have no pullover. You know I have been his momma, brother for you know 40-50 years and here we go and the

next thing I know is that the bird flying down the street has more power than I do because at least they can shit on you and get away with it.

Yeah.

But when somebody can come up and tell me, I got to move out of the house I was born in because they got some kind of signature from somewhere else and this man has no clue. Screw that. The truth is, if I wasn't here, he'd be in a nursing home. Do I have to go to the court and become his fact legal whatever, some kind of mother, brother officially?

Well, you know even though he's got some immobility he's of completely sound mind.

No, he's not.

I think a judge would probably say he was.

I am sorry but people that don't deal with it for 13 years walk and say.

All I know is that I take care of his primary healthcare needs.

Right. And somehow the flow of what you do, you have I guess a drifting effect that you don't know about.

That could be.

Somebody does have to have a foot on him. And yet it's a free moving foot and I give him lots of float room and I don't use that unless I have to but now it's just;

Bye Ron.

You blink and life changes. Well, okay, I guess I'll do some creative lawyering.

Yeah, that sounds like you might need to contact a lawyer.

I'll call up something that you don't want to happen to you. Everybody has their little kinks that you can hurt them with.

Well, now that's kind of making me concerned when you say something like that.

If I have to tell this judge, I will put you out on the street and or whatever you know I will do what I going to do.

Who are you talking about?

I am talking about the care for him. I am still his mother-brother and I am going to stand where I am because I know what my mother taught me to do and if he's pissed at me, so be it. I will still stand where I have to be. Okay doke; I will do what I am going to do again. That's just a pain in the ass.

Do you feel safe and protected?

Yeah. I am still; I think a wrestler and I think I can; put him in a guillotine!

In a guillotine, is that what you said?

And make him scream for help.

Okay. I think there's a lot of financial issues in who is in control of the money. I think Louis feels like since he has taken care of him, since his mother died, that he probably deserves some of Ron's money. I wanted to ask him oh you are his mother-brother, what do you do for him? Because Ron toilets himself. He gets a bath aide couple of times a week. He's pretty self-sufficient. If things are sketchy I really am beholden to call adult protective services, and they will investigate and make sure that he's safe and nobody is taking advantage of him.

Patricia changed her plan to be able to get more affordable medicines I think and in doing so she; we don't take her plan, MDTU does not take her plan. So, she had to get a different primary care provider.

Yeah, she finally got her insurance through. They sent her a card.

Okay, good.

Yeah.

So, she's seeing another doctor now.

Yeah. She went to her the other day. Well, she is a woman doctor over here on Franklin Street over here.

Yeah.

I can't think of her name.

How are your spirits? You seem pretty good.

Yeah. I have been doing fine.

Enjoying the fall and enjoying thanksgiving time.

Yeah. I had plenty of thanksgiving.

You did.

Yeah.

Good for you.

I am just going to be glad to see summer get here again.

Well, I am going to send the lab out here to get your lab work, that's your prescription because you will need that. Here they come.

Here they come.

Here we are. Hi. Surprise. How are you doing?

I will just say I am half and half.

You are half and half.

Yeah.

All right. Well, we are just wrapping up Pattie.

Here a while back my; People from the church come over here and prayed for me and put his hand on my stomach, my stomach was hurting you know, burning, you know it does that sometimes. And the first thing you know, boy it just went away.

That's amazing.

Didn't it Patty?

Yeah.

How are you doing little lady?

I am hanging in there.

You know the last time;

But I got that Dr. Christina Gerlin up here at Dr. Roy's office, no pain doctor. She won't prescribe no pain medicine.

No pain meds.

He had a bunch of mucous caught in his chest and it was blocking his airway and he totally passed out and was blue and he couldn't breathe. And so, I hurried up and got the morphine and gave him some of that.

The on-call nurse was called and his stats were down into the 50's. He had turned blue up through both of his arms, his chest and he was incoherent. The family panicked and called 911. And then when they got there, they couldn't find DNR. And, you know with emergency personnel they are required to do CPR without a DNR in the home, so it's unfortunate they were struggling to find it.

They wanted to know if Roger wanted to go to the hospital. And I said well, I don't know, I can't, he's not responding, so I can't ask him. So, they waited around, waited around and finally Roger came to and they asked him, he said no, I don't want to go to the hospital.

Something that the on-call hospice nurse said to me was he used to be an ICU nurse, and he said sometimes when someone was in a situation like that, we over-treated them and made it worse. People

jumping in and doing things and he said it was very interesting for him to watch because his body took care of it.

Yeah.

It took a little bit but left with some very gentle support. His body took care of it. And I think at this stage of his life, letting his body do what it needs to do either to come out of a situation or to let go, and his body is the only thing that knows which way that's going to go.

Hello, good morning.

Good morning.

How are you guys?

Hanging in there.

Hanging in there. Nice to see you.

Yeah.

It's been a little while.

A lot better seeing you walk in the door.

I am glad to see you. Let's talk first;

I am glad to see you.

And then we will kind of talk about your stuff. How have you been?

Hanging in there.

Hanging in. So, you are coming back to me.

I sure am and I am happy.

You are happy.

Yes.

What happened?

Well we had this one insurance that dumped me.

Yeah.

Then now I got this United healthcare now so I got you.

Okay. So, did you; when you changed insurance and you went to another provider;

Doctor.

What happened?

I don't know. They didn't take the insurance no more.

Oh, they didn't take your insurance anymore. Did you ever get to see that person?

One time.

Just one time.

Yeah.

Is it a better insurance for you covering medicines and covering stuff?

Yeah.

So, that's why you switched to it.

Okay.

It's like a silver plan.

A silver plan okay.

But it's a good plan.

Good. Well, I am glad.

I have to pay for it but it's good.

You pay for it.

\$236, Almost \$237 a month.

A month.

A month yeah.

How's your sugar been running? Because it was getting low there for a while.

Well, it's been real good. It's been like 120, 125, 130.

Perfect. Did that doctor do any lab work on you when you were there that day?

Yeah, they said my sugar was down and everything.

Yeah.

And he said starting sweet and stuff like that. Bring your sugar up.

Okay.

I said why heck. I eat my food.

You have good appetite.

I have been getting good appetite honey and I bought four slabs of ribs and cut them up and put them in freezer and had baked potatoes and ribs.

Good one. I bet Wink likes that.

Yeah.

All right. I will see you guys in a month.

Alright; I am glad to be back, man

Is he getting any feeds or;

Yeah, I am still feeding him, and he's still going to the bathroom and this morning [unintelligible] earlier he had wet the bed.

Okay. That's unusual for him.

Yeah.

Because he's not fully aware of what his body is doing, you know his brain is just not functioning like it was, you know even two weeks ago.

he need to sleep a lot.

Sleepy a lot.

And I heard him last night talking but he wasn't talking to me.

You are fair. You are having any pain?

No.

No. Okay.

He's definitely declined a lot.

Yeah.

He can still hear everything that you are doing and talking about, so even if he's not you know awake and wanting to see the baby I am sure he still loves to listen and hear everything going. So, people hear right up until the last minute before they die, so keep talking to him and loving on him.

Is it coming?

It's coming. And then he can really rest. He's been a huge fighter. I mean, he's fought and fought and fought and fought.

Yeah.

Yeah.

What can I do for you?

I don't think anything.

Okay. Just be in touch. I will check in next week again. And you've got all our numbers and just; well I don't have any advice, I don't know. Just be you. You are doing great.

Okay.

Okay. Call me.

All right. Happy Valentine's Day.

Thank you.

Enjoy that sweet baby.

So, the last time I saw Ron I was worried because Louis was talking about he was going to go to his lawyer and get the money from Ron and I was worried that; I just needed to make sure that Ron was financially protected from Louis. So, I called this case worker who called me back and reassured me that he has a financial power of attorney, it's a family friend who is legitimate and caring and protects the money. So, Louis cannot get his hands on it and they've been down this road over and over again with Louie who feels like he deserves some kind of financial compensation for "taking care of Ron". We agree that we would just continue to keep monitoring the situation so he's protected financially, but we will just make sure that he's not being too mean to Ron and definitely of course anything physical will act on, but right now it's just two brothers who fight.

Whenever he's feeling like he's just air hungry like that, that's his time for morphine.

It's coming baby. I am happy to do it, but he just probably want you to do it.

I knew too. [unintelligible]

Get your hands on you.

Okay.

I know honey, I know.

You think you can rest now? Okay, all right baby, I love you, and I will see you in a couple of days.

So, I guess they had a good night last night and stayed up till about 3:00 in the morning talking and he was comfortable and they went to bed and she fell asleep and when she woke up at 11:00 this morning, he was gone. Yesterday was a really tough day and he was really, really struggling and it sounds like maybe that the last part of his life was a little bit more peaceful. I am going to head over there and just pay my condolences. I just want her to know that I care about them and I care about her and I care what happens to her and that I was glad to be part of their life. That's what I want her to know.

I think this kind of a service means so much to families. When you go to someone's house to see them, you are telling them I value you enough as a person to come see you where you are.

Oh sorry.

It's not spoken, nobody talks about it. But I think these people feel like I am kind of special, you know they are coming to see me or at least someone cares.

Lily?

Yeah.

Lily it's Jessica from MDTU.

Okay.

Hey sweetheart, how are you, sorry to wake you up. It's just so cold out there, oh my gosh. How have you been? Tell me about your hospital's day.

Well, I went in [unintelligible].

What's down your throat. Let's see what's going on.

I know my head's hollow.

So, you probably need a refill on your pain pills.

Yeah.

Yes.

I keep on trucking.

I know you keep on trucking.

So, I think ultimately the solution is there needs to be more people doing this. More and not just nurse practitioners. There needs to be more caregivers, more aides, just more people need to help these families.