



From Huntingtonland with Love

Play written for the World Congress on Huntington's Disease, Rio de Janeiro, Hotel Sheraton, September 17, 2013.

Book: Emilie Hermant, with the participation of Alice Wexler and Angèle

Translation from French: Nora Scott

Artistic advisors: Johanna Silberstein and Marie Piemontese.

CAST

Alice Rivières: Aurore Deon (on stage)

Alexandre Dumas: Jean-Christian Grinevald (via pseudo-Skype recording)

The plant: Marie Piemontese (pre-recorded voice)

Alice Wexler: played by herself (via pseudo-Skype recording)

Gospel singer: Johanna Silberstein (via pseudo-Skype recording)

Angèle: Johanna Silberstein (via pseudo-Skype recording)

Charles Sabine: played by himself (on stage)

The conference stage has been turned into Alice's bedroom. A sort of space capsule equipped with a comfortable bed, a bedside table and lamp, a laptop computer, books, a package of Frosties, a bottle of Cachaça, and two glasses. In one corner, a

houseplant, the same one that stood there, incognito, as stage dressing. The two screens used for the conference speakers' PowerPoint presentations will be important pieces in Alice's exploration. The first will show what is going on in Alice's computer, in particular her Skype connections. She will address indifferently her laptop or the screen (no need for remote control in Alice's world). The second is a notebook screen: words and expressions will appear as she writes them in her notebook. At the end of the play, this screen will be covered in words and key quotes that will comprise a leaflet distributed to the audience as a souvenir.

Alice is sitting in bed. She is wearing a T-shirt, loose-fitting white trousers and white tennis shoes; around her are spread the things typically needed for a comfortable life in bed. Notebook in hand, she checks off one by one the objects required for the exploration she is about to undertake. She is serious and somewhat agitated.

She turns on her laptop, calls up some music, Mozart, the larghetto from his 11th piano concerto, and sets her space vessel in order: She arranges the sheet and pillows, carefully lays out her computer, books, notebook and pen on the edge of the bed. She puts on her glasses, savors the piano's entrance. She gets up for the package of Frosties and a glass of Cachaça, takes a swallow after having toasted her invisible gods, and switches on the bedside lamp. She's ready to go.

Alice clears her throat, turns the music down and then off, clicks on her laptop. Skype can be heard ringing, a man's voice answers.

ALEXANDRE DUMAS

Allô?

ALICE RIVIERES

Hello, Monsieur Dumas... do you hear me?

ALEXANDRE DUMAS

Yes! Who is it?

ALICE RIVIERES

My name is Alice Rivières and I'm calling because I would like to ask your advice... You see, my mother has a genetic disorder that is gradually destroying her faculties, both physical and mental... It's hereditary and is passed on to the children in one out of two cases. Three years ago, I wanted to know if I would be affected as well. So I took a blood test and learned that I had the same genetic anomaly as my mother. Doctors are in no doubt that I will get sick as well. They say also that there's no cure...

After the test, I succumbed... not to the illness, but to an endless series of questions.

For instance:

How do you think when thinking breaks down?

How do you think about how to think when thinking breaks down?

How do you think about how to think when thinking breaks down when thinking breaks down?

The questions appear on her notebook screen.

Meanwhile life is going on without me... You get the picture?

ALEXANDRE DUMAS

Perhaps, but why did *you* have the test?

ALICE RIVIERES

Well, that's it, I don't really know any more... that's the problem. The test didn't give me an answer, it gave me a riddle, which is: *What am I supposed to do with all this?!* The biggest danger isn't so much the illness in itself but the risk that the illness gets separated from my intelligence, and that would kill my own intelligence and the possibilities of intelligence that this disease contains.

Monsieur Dumas, you're the author of the *Count of Monte Cristo*, where you tell the story of Edmond Dantes, the victim of one of the cruellest injustices ever, who spends one-thousand-five-hundred pages twisting his fate every which way... In other words, you're the expert on this kind of contortion that allows someone doomed by fate to turn it into a fantastic adventure, a life-giving power...

ALEXANDRE DUMAS

[*Breaking in*] You learned that you have a disease or that you have a genetic mutation?

ALICE RIVIERES

Both: A mutation that *leads to* a disease.

ALEXANDRE DUMAS

And yet they aren't the same thing... If I were to write a novel about a character who knows he carries a mutation that one day is going to make him sick, I'd explore all the possibilities that this genetic abnormality allows. What does it do to the mind, to the body? What does it reveal about hidden aspects of the world and of people? Things that frighten us because we don't understand them. Do you know what we do with things we don't understand, Alice Rivières? We make them into anomalies and sometimes... diseases. And yet we're talking about life! Life at the outset, life during and life after. Life that grows in spite of everything. Like a plant, even when there's nothing, no sun, no soil, nothing, that shoots up and up and, little by little, becomes the very intelligence of the shoot!! That's what I wanted the story of the Count of Monte-Cristo to be about.

Now you must excuse me, I have to go because there's another call waiting... So many questions... Good luck, Alice!

He hangs up without waiting for an answer.

Somewhat punch-drunk, Alice writes on her notebook screen: "intelligence of the shoot".

She wanders around and stops in front of the plant.

ALICE RIVIERES

Slightly hesitant.

OK...You, for instance, could you talk to me about the "shoot's intelligence"?

THE PLANT

"My shoot's intelligence" – that isn't very good English, but of course, he's right, Dumas: your problem, now, isn't if you're sick or not. Your problem is whether or not you are going to make a success of your mutation. You see, my problem isn't light, water or nutrients, but the way I adapt to them all. And I'm not talking about a mad rush to survive. It's just the reverse. With each tiny step, I strive for fullness of life. And I don't always find it. But if I look carefully, I often end up at a place where several possibilities intersect. Possibilities that suggest elsewhere I hadn't foreseen. I'm not looking for fulfillment for its own sake: do I look like someone who wants to colonize a space, to give high yields? To improve myself? No, my life is an oneness with my surroundings, with what touches me, brushes against me, guides me, accompanies me, including the sun so far away. I turn it into a personal contact. Do you know how to do that?

ALICE RIVIERES

I'm not really sure I want to feel all the unknown things that are going to exist within me... the very thought panics me.

THE PLANT

You'll stop being afraid if you *start by* feeling. These tiny insistent tremors -- don't shut them out, welcome them, be hospitable. We're talking about one of your senses. You possess it or it possesses you... It makes no difference to me.

ALICE RIVIERES

Lost, unbalanced

Wait a minute... All of a sudden I don't really know what a sense is.

Skype rings while she writes in her notebook: to possess a sense? ...

She turns to answer.

ALICE WEXLER

Hello, Alice?

ALICE RIVIERES

Alice! Its good to hear your voice!

ALICE WEXLER

So, how's your research going?

ALICE RIVIERES

Hey, your timing's perfect! Alexandre Dumas advises me to take an interest in what is growing and evolving because of the mutation, not like a disease, you see, but rather like a life force. And now my houseplant suggested that I start with feeling what's growing inside me, whether I want it or not... In talking with families, have you heard anything about that?

ALICE WEXLER

You know, I have mostly heard about sorrow and loss. I know you don't like that, Alice... But everything people hold dear, everything that's important to them --- ruined and even torn to shreds, annihilated by the consequences of this disease.

ALICE RIVIERES

I admit I tend to avoid the subject... Perhaps it's because I'm afraid of falling down into a bottomless hole, as Alices often do!

The Skype connection breaks up in a little burst of static, and Alice disappears from the screen.

Alice? Alice?

I've been wondering: Is weeping something we should do in private? Or is it something we can share, beyond our close family and friends, beyond those who are affected with Huntingtons? But what good would that do? Ease our hearts? Let off steam? Create a vast lake of tears?

A rhythmic shaking of chains can be heard. A voice calls out.

THE SONG

Alice, wait... Calm down. Listen. What you're looking for may not be where you think it is.

A mans' voice can be heard singing over the sound of the chains, and a choir answers. Here the lights can dim for a moment, giving Alice time to take in the lesson conveyed by the freedom song she hears.

ALICE RIVIERES

I'm going to have to learn to sing... but not alone. I need to discover how the "we" can sing, sing everything we miss. For those who are gone and those who keep going – our families full of holes, torn apart, our loves lost, our failing faculties, our powerlessness as doctors and scientists searching and searching again, and having to start over... And to sing everything that is pushing at our backs, like that to drive us forward, beyond where we are today. To sing sorrow as well as desire. Never the one without the other. Never the incarnate, anchored, rooted power of the one without the pushing and the revolt of the other, to detonate the scandal of our condition in the face of the whole world.

On the notebook screen, we see "learn to sing".

She turns to the plant.

Isn't that right, plant?!

CHARLES SABINE (in the audience)

You're rushing things, Alice Rivières!!!

ALICE RIVIERES

True, but how could I do otherwise? It's in my nature! I'm just DNAed that way.

CHARLES SABINE (in the audience)

What exactly do you mean by "the scandal of our condition"?

ALICE RIVIERES

"The scandal of our condition"? I'll tell you what I mean.

Imagine for a minute a caterpillar having to go through its metamorphosis without a cocoon. Everyone would be disgusted. No matter that in the end there was a butterfly. Because you know what happens before a caterpillar becomes a butterfly? She becomes mush. A mush of herself. Without a cocoon to shield her, everyone would be horrified by this spectacle. It would be even worse for the caterpillar, seeing herself turning to mush without the protection of her cocoon! It would be enough to make you crazy, or suicidal, or homicidal... The scandal of our condition is having to go through that *without a cocoon!*

In fact, we were just talking about that the other day with Angèle... You remember Angèle?

Angèle appears on the screen.

ANGÈLE

It's true. It's enough to drive you crazy. I'm just beginning the disease and I can tell you, it's a catch-22: either you don't do anything and you're swallowed up (and accused of apathy to boot), or you fight back and you're accused of being irascible. That's the scandal of our condition too.

What we need is to be able to say *the right* dirty words at *the right* time. Figure out, in any case, ways of expressing our anger without having it come back at us.

ALICE RIVIERES

Alice writes in her notebook:

“Learn how to make a real cocoon – a dwelling for our metamorphosis...” and then “Know how to express legitimate anger”.

Go ahead, Angèle, come up with some good swearwords.

ANGELE

OK, I'll try...

She begins in a whisper

Fuckin'... fatigue

Fuckin' black thoughts

Fuckin' fear

Fuckin' being out of step

Fuckin' anxiety

Fuckin' desire to do harm

Fuckin' desire to do myself harm

Fuckin' slowness

Fuckin' hurry

Fuckin' hard time completing my sentences

Fuckin' hard time understanding what I'm supposed to do

Fuckin' clumsiness
Fuckin' complicated world
Fuckin' steak to cut up
Fuckin' funny looks in restaurants
Fuckin' stairs to go down
Fuckin' user's manuals
Fuckin' inability to explain what's going on.

Fuck you very much.

ALICE RIVIERES

Alice listens to Angèle, while eating Frosties as though it were popcorn, nods, approves each burst of swearing, before gradually being swept up in the anger herself:

No but it's true, its really fucked up, really unfair, what a motherfucker of a shitty deal. I feel like knocking all those assholes on the head, then burrowing into bed without someone always hassling me to stand tall, to get out of bed every morning, to go here, to go there, to be sociable, to have opinions, to talk sense, to be a good friend, a good lover, to eat neatly, not to break things, not to choke until I vomit in the restaurant, not to fart, to wash, to comb my hair, ah, there we go, to *comb my hair*, but who gives a shit about combing one's hair!!!...

Ahhh... Thank you, Angèle, that did me good.

Angèle disappears.

Learn to express legitimate anger. Like doing speech therapy, relaxation therapy, yoga, sit-ups, cycling, jogging... Practice legitimate revolt. Do it proudly, with head held high. Not to be just a suffering container. And do it *with* those around us, so that they won't be the systematic target of this anger...

CHARLES SABINE (in the audience)

That's pretty wishful thinking.

ALICE RIVIERES

Absolutely. But I can't help it. It's DNA-collateral-damage. Learn to live with it, my friend.

In fact, come up here, Charles.

She calls him onto the stage and has him sit down.

Can you tell me how we could make a real cocoon, one that would protect our upcoming metamorphosis, our Neuro-Evolutionary Long March?

CHARLES SABINE

Your Cocoon thing already exists: it's called *care*.

ALICE RIVIERES

Ah, yes, the famous *care*... Did you know that French doesn't have a word for *care*?

For all those things that don't come under cure properly speaking... such as kindness, attention... love, too.

CHARLES SABINE

Well, care is all that, absolutely. But not only.

ALICE RIVIERES

Physical therapists, nutritionists ... sexologists, sports coaches...

CHARLES SABINE

...All sorts of *counselors*, for speaking, swallowing, breathing...

ALICE RIVIERES

Wheelchair profs, engineers for our future *communicators*, very good dry cleaners?

CHARLES SABINE

Yes, it's all that, too, but not only!

ALICE RIVIERES

Well, then, ... hmm... I give up. Wait a minute...

She serves a glass of Cachaça for Charles and her.

A home disco?

CHARLES SABINE

A steaming bath always ready?

ALICE RIVIERES

Consensual sex on demand?

CHARLES SABINE

Daily massages?

ALICE RIVIERES

Five-stars chefs to cook us liquefied dishes so delicious we would be the envy of all?

CHARLES SABINE

Thick lawn as far as the eye can see, so we wouldn't worry about falling and would never do ourselves serious harm?

Goes back to his seat.

You're right, we need all that, too. But in this cocoon, what we need above all – I'm going to tell you – is *to be able to move!* We need the freedom of movement!

ALICE RIVIERES

Mmm... It's true that everyone has to get moving, not only the HD person. Everyone around them, everyone connected with them... Close or not, everyone is forced to get moving.

There should be a word for this *Care cocoon*. Wait a minute... I think I've got it:

Cocoocare!

CHARLES SABINE

Cocoocare... Not bad!

ALICE RIVIERES

A Cocoocare capable of protecting our ongoing mutation and even of... anticipating it, escorting it... Dancing with it!!

ALICE RIVIERES

Everything dances, not only the body. Our mood dances, our emotions dance, our thoughts dance. Desire dances, relations with others dance. Not to mention our energy, that can really dance!

"The flowering of our mutation"... an endless ballet!

No one knows their part ahead of time, beginning with the HD person, and no one around them knows either! Watch out for those who think they know ahead of time; they might become stiff. You need to be flexible, to put your inhibitions aside (great, that's good timing), not try to control your movements... and follow [*here she does a slow-motion moonwalk*] the lead of your new-always-being-discovered-landmarks...

Long pause while she looks out over the audience. Walks to her bed, closes her laptop and puts it under her arm, switches off the bedside lamp. Returns center stage.

Learn to move with your whole being... Learn to do it together, with those around us.

Learn to make everything dance, calmly, with tenderness. Without fear, that's it.

Without fear.