

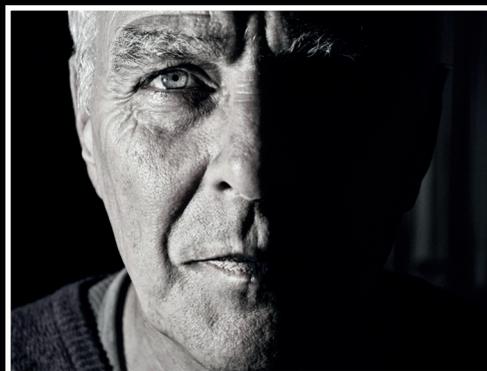
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OUR STORIES

HUMAN RIGHTS AND OLDER PEOPLE IN EUROPE



A DOCUMENTARY THEATRE SCRIPT

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To learn more about the project: <http://twomoons.eu>

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CONTENT:

INTRODUCTION TO THE TWO MOONS DOCUMENTARY SCRIPT	4
DEVELOPING THE TWO MOONS DOCUMENTARY THEATRE SCRIPTS	5
Script one:	6
Script two:	23

INTRODUCTION TO THE TWO MOONS

DOCUMENTARY SCRIPT

Two Moons is an educational resource to inform and enhance the knowledge of older people and wider society of human rights and how these rights should operate in practice. It creates a space for older people and the wider public to witness situations where older people's rights have not been upheld.

The objectives are:

- To provide learning opportunities in the field of human rights as protected under the European Convention on Human Rights (ECHR) and the United Nations Convention on the Rights of People with Disabilities (UNCPRD).
- To empower older people to assert and claim their rights.
- To shine a light on the challenges older people face, in having their rights met in everyday life.
- To make visible to policy makers, health, social care and legal professionals and human rights advocacy groups where public institutions are failing in their obligation to protect older people's rights, empowering them to become agents of change.

The four interlinking education resources being developed include:

- Two Moons Booklet: My Human Rights, My Wellbeing
- Two Moons Our stories: Human Rights and Older People in Europe: A Documentary Theatre script
- Guide to hosting the Two Moons Documentary Theatre and Talkback
- Listen to my Story: Human Rights and Older People's Experiences, individual audios and learning packages.

DEVELOPING THE TWO MOONS

DOCUMENTARY THEATRE SCRIPTS

Documentary theatre is theatre that uses pre-existing documentary material (such as newspapers, government reports, interviews) as source material for stories about real events and people. The Two Moon Documentary Theatre script brings to life, stories older people tell of situations where their rights have been infringed. Monologues are used to convey the stories and these are linked together as a play in the scripts.

A reading of the six monologues was carried out in each partner country, Finland, Ireland, Italy and Romania. A total of 32 people attended the readings, 23 older people and nine professionals. There was unanimous agreement that the monologues used in the documentary theatre script were easy to understand, felt authentic and reflect situations that older people encounter in all four countries.

Two different approaches were used to link the monologues into a play. These different approaches emerged from cultural differences and social norms around knowledge transfer in the different partner countries.

1. Script One used Elsa's monologue to connect the other five monologues. The rationale for this approach centred on Elsa's voice as a teller of her own story from the perspective of an older person and as an observer of how the human rights of older people are infringed in her role as home care nurse and volunteer with a peer support group for people experiencing family violence. This made Elsa well placed to take on the role of advocate and in a position to empower the other characters/storytellers. While Script One concludes by citing briefly different human rights infringements experienced by the different characters, it is left to the Talkback session to explore in depth with the audience human rights infringements associated with the different stories.
2. Script Two introduces an advocate as the narrator linking all six monologues into a play. The advocate outlines explicitly, issues concerning human rights infringements that the audience should consider when viewing the different monologues. These are explored further in the Talkback.

Script one:

Our stories: human rights and older people in Europe

This script for this play incorporates six monologues, five are standalone the sixth, Elsa's monologue, links the others together as the advocate. The performance of the play takes approximately one hour. Each monologue takes approximately 10 minutes to perform and they can be used individually.

ELSA: *(Enters with a medi-bag and holding a phone)* Password. Password. What's my Password? *(Addressing the crowd)* Do you find it hard to remember your password? I've passwords for everything. So, much to remember these days. *(Another attempt fails. Suddenly remembering)* Of course, I was clever with this one, so I wouldn't forget *(laughing at herself, and spelling out)* W I N T E R W A R. You see during the Winter War "No-one was left to survive alone, no-one was left behind". Right now we're facing another Winter War - we just don't realise it, and we're leaving the ones who need our help most behind. *(Checking her schedule on her work app)* 1...5....8...12... - that's 12 clients I have to see today. Do you know that I'm regularly asked what home care is like today and I am direct and blunt with my reply.....it's horrible, just horrible and unethical. Care work is demanding. 12 clients today alone. "The weakest are left to survive alone." So many of my colleagues are thinking of changing profession. They've had enough. We see the agony and distress in our patient's eyes and we in turn are anxious and upset having to leave out clients alone in their homes. "The weakest are left alone.". I sometimes feel powerless to change anything. There are so many day to day violations of common dignity, gross violations. I was once at a training given by a gerontologist who told us that the smaller the circle of life becomes, the more you need to feel safe. That has stayed with me since, and I strive to live my life by this code. Other people make you feel safe. We are dependent on those in charge, housing agencies, police, judiciary and our health care system. If you're living at home and you're unsafe, does it make sense to stay there? Take Chiara for example, she has her own battle to contend with, but I'll let her fill you in, because I've a million things to do before I even start my day. Coffee first though! *(Exits stage)*

CHIARA: My doctor thinks that I'm in my 80's, but I'm not, I am 79 years old. My husband passed away four years ago. And now I live alone. My life has been a struggle but there were good times too. Would you believe that I've had thirteen serious operations throughout my

life? The only one that ever really worried me was the heart surgery. There was a serious possibility of me dying. But I have always pushed through and survived. (*Contemplating*)

As soon as I got married, I went to live with my in-laws in the country. They were all men, and we looked after each other. They were good to me, and I to them. Human kindness is very important to me. I like to help others. (*Pause*) Here in my apartment building I do my best to get along with everyone. Naturally there are disagreements and heated discussions. If something needs to be said, we say it. It's the best way. Once my TV was stolen, and I knew who the thief was – it was the lady on the first floor. She hasn't had too much luck in life either. (*Pause*)

There was a time when I was very down and I cried a great deal. My daughters and grandchildren are very good to me, and they helped me get through it. My granddaughter tells me, "No one makes macaroni the way you do, grandma" I adore them. I spend Christmas with them. My friend Vittoria comes too. She has no one. But, she's part of the family now. She's 89 years old and fiercely independent. She likes to do her own thing. If she doesn't get to the cemetery three times a week she goes crazy. I don't feel the same need. I visit my husband's grave on and off. We were married for 50 years. He smoked so much that he burned his lungs out. The doctor told him, so many times, "If you stop you still have a chance. You still have time". He never stopped. (*Pause*) That's life!

But then this bad thing happened. I was heading out to do my shopping when I saw two men coming up the corridor. They informed me, "Madam, we are from the water company, and we need to do a water check." Vittoria was also with me and so I let them come up to check the water pipes. They had badges. They wore normal clothes. One went into the kitchen and my friend stayed with me. Then the other one came up behind me with a photograph of my mom and one of my dad ... and he puts them like this ... one here and one there ... and I said to him: "Excuse me, but how did you get the pictures of my mom and dad? And he told me to "take off my rings. I did everything he asked. All I had left was my wedding ring. All of my rings were stolen from me. And then again, he asked, "Do you have any other gold?" "Yes." I said. I had a bracelet in my drawer that my husband had given to me on my honeymoon. I took it out of the drawer and gave it to him. Then he asked me again: "Do you have any money here?" "Yes. I have four hundred euros." I gave it all to him, as if it were a normal thing! It was like they had hypnotized me. Then as they were leaving, I suppose I snapped out of it, I don't know, I grabbed him by the hand just like that, and I said to him: "A curse on you for robbing me." I remember he had gloves. I grabbed him by the hands like that ... my friend was with me ... and I started screaming ... I went down the stairs or by the elevator, I

don't remember ... I just know that I started screaming and all the residents of the building came out and were down stairs. I made gestures, screamed ... Some women shouted: "Let's call the ambulance! ... Let's call the police!" I told the ambulance people when they arrived, "I'm not going to the hospital! If I have to die, I'll die in my house!" In short, the whole episode really destroyed me! In the evenings I say to myself, "Don't think about it!" But when I go to bed, I think about it. "How on earth did I not realise!" But they must have done something to me because I said, "Yes." If I said No they might have beaten me! One had a cap with a visor. If I saw him again, I would scratch him like a cat! I feel angry! Now when I see things like this on television I say, "Look at how I ended up as well!" Unfortunately, you hear of so many stories like this! What kind of people are they? Taking advantage of the elderly! How can they do that? Steal what little I have. All my life savings gone. It's like stealing an old man's bread. Even animals don't do that. I get so angry sometimes! ... *(Pause)*

Now I'm afraid to leave the house. It's not so bad when I am out and have distractions. It's only when I'm at home and I start thinking: "But why did something like this happen to me?" I shouldn't carry my bag outside, I know, but I do. If I'm here alone at home, I can't stop thinking: How did they do that? ... They could even have beaten me badly! *(Pause, worried)*

Then there is also the man who lives on the ground floor. One day I went down to hang the laundry in the common room with Vittoria and he accused us of being delinquent thieves who robbed him. "What have we stolen from you?", I said in our defence. "My wife's dress." he said wickedly. I was so annoyed that I said, "Me? Your wife's dress? Do you know what I would do with your dress? I would wipe my ass with it!" Then he asked me to hit him. Vittoria kept saying "Chiara come away, come away? Let's get out of here!" And I said: "But why do I have to leave, I haven't done anything wrong?" And with a warning finger he said: "Just try touching me and your life is over!" We left and immediately I phoned the building administrator and let him know how we were threatened and that if anything happened to me, he'd know who to be looking for. Then one day we learned that the man's daughter had died very young and that helped us understand his behaviour and mental state of mind. *(Pause)*

And then there is also that boy from the second floor, who deals drugs. One day I saw him unhinging the main door. "Well, what are you doing with the door?" I asked. "I'm taking it off because it has to be open." he said. "You put the door back where it was before, it must be closed." "No, we have to keep it open" he said. And then on the way to the elevator, he tried to punch me! Fortunately, he missed me. The punch was thrown with such force that it left its impression on the elevator! He wanted that punch to hit me! .. And what did the police do? They told me, "We know he is getting treatment. Just make sure not to get on his nerves..."

because when he is like that he could kill! "(Pause) Now in the evening I don't go out because there are always gangs of boys going up and down the stairs. They come here to get drugs. Unfortunately, life is like that! When my husband was around, we lived it up! But I'm happy to stay here. I want to stay here. It's still my home!

Elsa enters sipping from a takeaway coffee cup. She is very busy, but has the air of efficiency about her.

ELSA: (*Chatting in a relaxed manner to the audience*) I can tell you that the people making decisions and planning our work are not thinking of it from the older person's perspective, like, what would increase their feeling of safety. It's all about efficiency. Visiting someone you don't always have time to even check whether the client has eaten or not. It's really like the Wild West. You never know what to expect. I am forever in a hurry. Once again someone has planned my day with too many client visits. I only ever have time to check on the most important things, like, if they've taken their medicine. I can remember a time when I often found myself baking or listening to music or maybe even looking through a photo album with my clients. The work was so much more empowering then. (*Laughing*) Of course, I was younger then, but I don't ever remember being as exhausted by it all as I am now. It feels horrible leaving them there, when you see they are distressed and need much more care. There's just no time. And on top of that we are caring for an ever increasing number of people with dementia. For those older people the experience of a stranger coming into their home is very scary and unsettling. And even worse, it can be a different person on every visit, because the home care employees change constantly. "The weakest are left to survive alone". But, I still find my clients' resilience and determination an inspiration, and the good fight must go on. (*She takes a big sip from her coffee, bolsters herself and heads off to do her work*)

RUBY: (*smiling*) I was lucky to have a child. The period of motherhood, school and all the things you do with your children was a real blessing. I was 35 and my husband 40. We bought an old building and turned it into a bed and breakfast. Then I got involved in fighting for the lack of services; for children, for mothers, for everyone. (*Pause*) I also decided to go back to university and while I was studying, I worked in a job that promoted the rights of people with disabilities. (*With strenght and determination*) My God, how many injustices there are for the disabled! ... I fought for them ..for many years! (*Pause*)

However, when I was only sixty years old, I was diagnosed with early Alzheimer's and I immediately realized that I had to fight for my rights just as I had fought for disabled people's rights! Because when you're diagnosed and you don't know where to go, when you come home and you sink into fear and depression!... and there is no one who can give you advice. I gave up my job and all my commitments.. (*In a pressing way*) because I was confused, because I was scared, because I couldn't remember! ... (*Determined*) But I should never have given up my job; I should have said, "Alzheimer's can happen to everyone!" But I didn't! I was afraid to say it, I was ashamed! ... Alzheimer's is not like cancer. If you had cancer, you would talk to your employers and say, "I have cancer" and they would say, "I'm sorry!" but they would help you. If you went and said, "I have Alzheimer's" they would immediately find a way to get rid of you. In fact, as soon as I left work, no one contacted me anymore. They all disappeared! ... (*Silence*)

In the end the doctor told me, or he told my husband, I don't remember, "We have to do something for Ruby, to keep her from falling into depression." I didn't realize it, but he was right. I was completely depressed! ... (*with exasperation*) But what was I supposed to do? The world had collapsed on me! ... (*determined*) Then one day I convinced myself: "Yes, I have to do something!" I phoned a centre for Alzheimer's disease and I decided: I'm going! I got into the car and drove thirty miles to this centre. But when I got there ... they were all ... I wouldn't say old ... but they all looked ... older than old! ... I went to a nurse for advice. Finally she told me: "There's nothing we can offer you here, Ruby. The only thing I can advise you is ... inform yourself - do your research." I thanked her and left. I sat in the car and cried and cried. I thought: This is my life now?! Is this what life has given me?! I finally found the courage to go home. (*Pause*) Then one day at the hospital I was telling my story to a nurse and she said, "I have a number for you. He is a professor at the University. Call him. He's looking for people for his Alzheimer's research using cognitive therapy." From that moment on, my new life journey began! (*Enthusiastically*) The therapy was absolutely fabulous! It completely changed my life! (*with growing enthusiasm*)... writing. Write everything! Write your day, every single thing you do – all to remain cognitively active! Keep your diary up to date- writing everything is very important! ... And not just writing, but also reading. Read a lot. I read all the newspapers. (*Pause*).

And I'm lucky, I have the love of my family! (*Pause*) ... But so many families right now are deciding, "Don't tell mum she's got it. Or don't tell Dad he has it!" (*with strength and determination*) But they're wrong! ... Why do you have to lie to your mother and not tell her the truth? If she had diabetes, would you tell her? If she had cancer, would you tell her? ...

Of course you would! ... Then why wouldn't you tell her she had Alzheimer's? So you could give her the opportunity to be informed so she could decide for herself, at least for as long as she is able! ... *(with indignation)* And then why should we be sent to a nursing home? ... Why shouldn't we live in our own homes when we have worked so hard? Proper assistance is what we need. Look at the train- Why don't they announce the stops on the train so I know where I am? ... Or at the airport? *(In an ironic tone)* When you ask for assistance at the airport? - the first thing that welcomes you when you get off the plane is ... a nice wheelchair! And then I have to tell him: "No, thanks! I was sitting the whole trip, now I would like to stretch my legs a little! "... Once in an airport a girl gave me a lanyard and I asked her: "What's that?" And she replied, " It's for people with autism or memory problems-you must put it on." I said *(ironically)* "A rope collar... like for dogs! How nice, thanks!" We also don't want special lanes either, just safety when we walk to the gates. *(With relentless determination)* Why should I be treated differently to Mary with multiple sclerosis? Or John with Parkinson's? Or Molly who has nothing? Why should I be different from all these people? *(Pause)*

My husband and I applied for home care and a nurse came who offered us personal care. But we needed help in the kitchen because I often burn myself and I can't do things in the right order anymore. Sometimes I forget I've left the oven on... The nurse listened and then she left. In the end I received an email. *(Sarcastic)* They offered us half an hour a week for personal care. Exactly what we didn't want! We asked for help in the kitchen. You pay taxes, contribute all your life ... And your rights?-You get a half hour from the welfare system ... *(Ironically)*. There are so many difficult things to do, so many problems and my anxiety rises in the fear of forgetting all these things to do. *(With restlessness)* Sometimes I wake up in the middle of the night and I don't remember if my husband is still alive or if he is dead! ... I reach out with a frightened hand to feel if he is ... if he is breathing ... thankfully ... he is still alive! *(Pause)*

And you must never forget the power of attorney, which is like a will. It's distressing, I know, but you have to seek some advice on some things, for when you won't have the mental capacity anymore. *(Determined)* I want to make decisions now about my future medical treatment.. But what if I forget what I've decided? Who will enforce my rights for me? For example, I don't want to be cremated; I want to give my body to science, if science wants it! ... And I wrote that in the power of attorney, so they won't forget it! Even if I do! Worse-off though are those unhappy people who are taken to nursing homes when they could stay at home instead and have assistance, not only from the health system but from others. *(Smiling)* "It takes a village to raise a child!" we used to say. Once farmers helped each other to save

the harvest. *(Smiling even more)* Maybe it takes a village to save an elder! This is my new life with Alzheimer's. It is not an easy life, of course... but it is still my life!

Elsa enters.

ELSA: Why are people with dementia, like Ruby, not treated equally and protected from discrimination? Surely, they have the right to be listened to and provided for like everyone else?

Elsa's phone rings. During this conversation she makes her way to the bench that Tom is sitting on and unsuccessfully attempts to eat her lunch.

ELSA *(Answering phone):* Hi Anna, sorry, My mouth is full.. you know yourself; I'm trying to catch a bite on the go. *(Listens to Anna who says she'll call her back)* No, no, you're fine, Sure, we're all busy, what can I do for you? *(Listens)* Ok, tell me a little about his case. *(continues listening)*

Yes, yes, Tom's case is a little complex alright, because he only has a small pension then he's definitely going to have to rely on additional social care and housing benefits to be able to live. He won't have much left over to survive on and it's affecting him psychologically, especially with all his efforts to get work. *(Her phone beeps, she checks her message)* Anna, I'll have to get back to you, I've to get to an appointment. Chat later. *(She hangs up, she rushes off, leaving her sandwich behind.)*

TOM: *(Tom has been reading his paper throughout Elsa's phone call. Looking into the audience and as if answering a question)* I guess you'd like to hear my story. Well the name's Tom and I am a contented 63 year old grandfather to my son's two children. I live alone, and just about manage to survive on a very low pension. I'm awaiting an increase, and how much or when, I still don't know. When I'm gone, I'll leave my home and the little I do have to my wonderful grandchildren. *(Ironically)* But, despite things I'm an optimist, an eternal optimist with a very impulsive streak *(laughing)*.

I am an electrician by trade, and I've worked bare-chested in war torn Iraq in 58 degree heat. It wasn't easy, but I managed to make good money, and like any young man I did a lot of stupid things. I had a full and active life back then. Now I'm out of work and I sit here doing nothing all day long. But, I'm not a lazy man and I desperately want to work. I retired at fifty,

but it wasn't my decision. You see I had a stroke at work, and a neurologist said to me "I'm going to make you retire, you haven't a chance of ever working again". That was really upsetting, I never wanted to stop working. I was very confused by his diagnosis – I had a problem using my hand correctly, but otherwise I was absolutely fine. I didn't want to retire. After my stroke I never talked to my employer again. I was so angry at the situation, and at him. In hindsight I was very stupid. I should have claimed compensation because the accident happened at work and I should have pushed for my employment rights to be upheld. But, at the time I didn't think about it.

You know I haven't been on a holiday for years. They used to organise these trips for older people. Now they don't do it anymore. It was the only time I got to go anywhere. We visited parks and forests and loads of old churches – to repent out sins (*laughing*). I'm not a religious man, thank God (*laughing*). I might mention his name from time to time though. I've always wanted to see France. I studied French in school, and I was quite good at it. I'd really like to explore that again, but I can't afford the classes. Wouldn't it be great if they were free, maybe? I would certainly go and learn then. But, it's all about the money. Just a little extra would go a long way and mean so much. Not to buy clothes or anything like that. I wear my partner's dead husband's clothes anyway. May he rest in peace. God bless him. I don't want much just a little extra to pay for French classes. Sure it would keep me off the streets (*laughing*). I'm forever walking, I prefer to walk everywhere. On my stroll today I bought a newspaper to look at the jobs section. Do you know what? As I was reading the advertisements, I thought to myself "Wouldn't I be a perfect employee, because at my age I don't sleep anymore, so I'd be able to work twelve hours a day. I'd be a very productive employee (*laughing*). I really want to work. I want to become a security guard; I've done all the necessary training too. Then I might be able to save some money and help out my grandchildren. I love them very dearly. They know I have no money, so they don't ask me for anything. This breaks my heart. My pension is much lower than normal. But, I'm not complaining about it, if I did I'd get nothing and things could be a whole lot worse.

I never contemplated old age as a young man. I got married to a wonderful woman and we had our son, that was like winning the lottery. But, I didn't know what old age would bring. Looking back I should have saved some money, I could have been more careful. If I didn't have a stroke, I'd be rich. But, life happens. I don't regret anything, what more could I want? My only wish is that my grandchildren will be healthy and have everything they want in life. I don't want anything for myself anymore. I have a home to sleep in and I get my meals at a social service canteen. It's not much, but it's okay, if I had more, I would help my family.

Christmas is an embarrassing time for me. I buy very small presents for my family and put them under their Christmas tree along side the other more expensive presents. This makes me so angry. I feel like a failure. I can offer nothing and have little to give. I feel useless, like a rotten cabbage. It would mean the world to me to be working (*Looking through the job advertisements in the newspaper*) A security guard in a bank? I'd have too many responsibilities. I could work in a Kindergarten, but with so many children, it's way too risky. Maybe a caretaker for an office building? I could do that, couldn't I? (*questioning himself*). I desperately want to work, otherwise I just don't know. I just don't know.

Elsa returns carrying a Yoga mat and sits on it to do some mindfulness/ meditation. This is her self-care regime that she uses to relax and destress. She narrates this story as if she is using the ritual to manage the stresses of her work and exorcise the many awful stories she hears on a daily basis.

ELSA: Imagine a man who wants to work and isn't allowed to even though his hand is almost normal now. So a doctor's decision made over 10 years ago stops him from working. Why shouldn't Tom have the same chance to work as everyone else and not have to live in poverty and be dependent on others? He's not obliged to work but he wants to and why should he be denied that right? At least he has a good partner to support him. Actually, in some cases the state encourages some partners to become carers because it saves resources. And of course, the person wants to take up the role because it's about caring for their dear one. But they definitely do not get the support and resources that they need....and they regularly become exhausted and burned out and when they've reached that point, they don't even see that they could be potentially neglecting or abusing their loved one. I remember this lovely older couple. The carer used to tie her husband who had dementia up to the radiator whenever she had to go to town. Fortunately, a care worker happened to visit when the lady was gone and released the poor man. When the wife returned she couldn't understand what the problem was at all. She talked to me at a later point and what she said amazed me, "What else should I have done? We had no food and I have no-one to shop for us...should we have starved to death or called the police to visit the supermarket for us? I often ask myself what would I have done in her position. What would you do? I know what Joan would do. But, I'll let her tell you. (*Elsa folds her yoga mat and makes her way to sit beside Tom on the bench*).

Joan enters as if she is doing her exercises in her backyard. She drags her left foot behind her. She sits often, but there is a steely determination about her.

JOAN: Well, I'll tell you a funny one (*laughing aloud*) I've got fairly bright when it comes to protecting my rights. I find that stubbornness is a great attribute as you get older. Two and a half years ago I had a stroke...No one told me which part of the brain was affected. Not until a year and a half later did I find out that it was my right side (*indicating the right frontal cortex*) and because of that I could have a false sense of my disability. I could think I was better than I was, and I did. Now I'd be normally arrogant (*laughing*) or whatever you like to call it. But, this was very different, I had a denial of my thing, my disability. They call it an acquired brain injury. I have to say when I was in the stroke unit I got very good service. I got medicated up to the eyeballs (*laughing*). I have a stomach like a cow, nothing upsets it, which is a great asset to have when you go home with a big bag of medicine. Along with that I got two weeks rehab, now when I say rehab I mean physio really – physio with a bed... After that I was able to walk to a degree, not wonderfully. But, I was on my own, and there was no arrangements to call me back, no follow up to see how I was getting on. To be honest I told them I'd be fine (*laughing*). I badly needed to get out of the hospital, you're up to here (*putting hand up over head*). In the end I had to get in contact with them because I was getting a hip replacement and the crowd doing the operation wanted a letter from my cardiologist. And wait until you hear...I have actually never attended a cardiologist..., he was a geriatrician, and he told me I would get my life back, but it took me awhile to realise you never get your life back. Anyways, he was a geriatrician, and not a cardiologist at all. The thing I would be worried about is that I know other people who have had strokes and they're not on the big load of medication that I am on. So, who is out there monitoring that? In all fairness my GP is, and I am lucky that I have a good GP. Now if you're going to take advice from me at all take this; once you get to be forty five or older, set yourself up with a good GP. If you don't like your GP dump them and try around for a new one, do it, because if you can't talk to them at forty you're not going to be able to talk to him if something goes wrong later down the line...isn't it terrible to think that you were thinking you were under a cardiologist's care for two years, and not knowing you weren't and no one saw fit to tell me. I can remember his voice saying all the right things and he was so very encouraging...Manners counts for a lot...not like the other fella in that rehab hospital. I had a call back to his clinic so he could discharge me. But, I wasn't ready to be discharged. So, I went to him and said I'm doing fine only there are two or three things I'll be needing... I need to go back to physio, as I'm dragging my left leg, it's sticking to the floor

and getting caught and I'm afraid it will trip me up, and I'm very tired all the time, which is probably from the whole load of medicines that would make you tired anyway, and I told him I was feeling quite depressed. And wait until you hear this, your man (*laughing*), this ole doctor sat back (*moving chair back*), and you know that we were about on the same level (*indicating proximity and height positions*), he never looked at me face to face, he focused on a place there on my breast bone with his eyes down kind of (*long pause, then mimicking*) 'Well WE don't know why some people feel tired after a stroke'... 'WE don't know why some people get depressed after a stroke'. (*Laughing*) I could have figured that one out for myself, right... I wanted something done about it, but I definitely didn't want to go on something that was going to make me addicted and give me another problem. As if I needed more (*laughing*). Then he sent me on a little trot down the corridor to assess my leg... (*Mimicking his voice and attitude*) 'Your leg is fine, go back to work'. And I was out like that (*clicking fingers*). Discharged. Imagine, three months after having my stroke. The book was closed on my care. He's some fool of a doctor.

Three days after that visit didn't I fall over my leg that was sticking to the ground and I broke my bloody wrist. So, I rang him and told him I want an apology from you, I don't know who you think you are, as far as I know you are a public servant paid for by our taxes, and if you don't, I'm going to make a fuss. He apologised, not in person, just over the phone... I let it go, but not until after suggesting he should go to the stroke information day run for survivors. They are absolutely brilliant, with all the crucial information you don't get from your own public health service. Anyway I told him you might learn a thing or two about strokes from a patient's point of view because you obviously know nothing about it. Of course he didn't answer to that, so I sent him a letter on that one, but I mean the arrogance of it.

My concentration was a big thing too... I was slipping that way; memory lapses, losing things. I found myself in town forgetting my purse, my phone and all sorts. I was very down and completely defeated in myself, and it wouldn't be like me at all. I thought to myself I need a bit of an assessment, so I went to an acquired brain injury charity service to get it done... they couldn't do anything for me because their cut off point is 65, and I had just turned 65. The thing is, if I had been given this information from the hospital right after the stroke two years ago I would have been 63 and could have had this kind of an assessment done. They never told me that I could have lapses, or what part of the brain was affected. I would have liked if somebody could say because of where your clot happened, these are the possibilities of what might happen. They had the CT scans, and with the advice of an expert, they should have been able to tell me what to expect to some extent and maybe even assess me to see was I

gone a bit that way already. Wouldn't you think in rehab they'd offer you that? But, no it was only the physio. From a psychological or a neurological point of view there was nothing, looking back it definitely was necessary. When I had the stroke I fitted in to all the services that were going, but as time went on they moved me into the elderly care sector, and you don't become a priority anymore, so effectively there is no funding for my age group.....it's very unfair because now most people work until they are 68. I'm still waiting to get the hip done. I did have an appointment for that, but they are still waiting for the letter from the cardiologist that I'm not attending (*laughing*).

I'm forever writing letters and emails now. I wrote to the fellow who saw me in Rehab to ask what was the protocol for stroke patients when they were discharged as regards physio. I took it up with the Minister (*laughing*) I'm like a dog with a bone, and I told him, "You have a problem with people on hospital trolleys blocking up your A&E's, let me give you a solution for that - give the likes of me that come out after a stroke access to proper physio, and we won't be falling around the place, and left in a mess. Barbaric!! I'll keep saying it, it's the lack of information...I shouldn't have to be going around looking for it...I should have been told what to expect from the start. I think it's my right to know everything about my own health. If I was unfortunate enough to have had the stroke on the other side of my brain, I could have lost my speech, well that was a blessing anyway that didn't happen 'because I live with a 23 year old and you need to be able to shout at a 23 year old (*laughing*) could you imagine that..... (*Extended laughing*) I'd have ended up living with me sister....oh Jesus no! I always reckon and this is not a word of a lie....I think it's my stubbornness that helped me to recover so well. I'm a noncompliant type. As I said earlier stubbornness is a great attribute to have when you get older. Now, I'm off to buy stamps.....more letters to write. (*laughing*).

ELSA: (*Repeating Joan's words*) Stubbornness is a great attribute to have when you get older. But, for some it is a luxury. What happens when you have to stand up for yourself and no-one is in your corner to help you, or worst they choose not to help you. If we don't use our laws and our human rights conventions as their purposes intended, we leave the most vulnerable to survive alone. (*She is cut off by her phone ringing*) Apologies, I have to answer this. (*Sits on Tom's bench*)

INGRID: It started when he began hanging out with the wrong people, when he got a job as a banker. It changed him; he started abusing alcohol first, then drugs, then me. My own son.

I got divorced when I was young; I had to get out, but my 2 boys grew up as happy and nice boys, especially the younger one; he always took care of me and his older brother and was very sensitive...and because of that, what happened later on was a complete shock to me.
[pauses]

You see, at 27, my son started losing grip of his life; he lost his apartment and his wife left him. That's when he returned to live with me... I barely recognised him. He was dependent on drugs so one time he asked me for great deal of money and I didn't give it to him. He got so angry, started throwing things and went to the balcony and threw down a chair. I was so embarrassed and hoped that nobody had seen that. And then he hit me.. and that was the first time I ended up with a black eye.. I didn't tell anyone...I just wore sunglasses to the grocery store and waited for it to heal before going anywhere important. I was just so shocked.. the change in him was so huge. It was like one day it was bright and then suddenly out of the blue everything went pitch black. He didn't even apologise. My son's aggressive behaviour increased and he hit me almost weekly. That's when I thought: I cannot take this anymore. So one day I called the police. When I explained the situation they.. *[pauses for a longer time]* they didn't take me seriously. They said that as a mother I should be able to control my own child and I should just kick him out. It made me so sad and anxious that the police would say this. Another time I called they said I needed to start collecting all the proof I had of the violence and only once I had done that, could I report the crime and seek a restraining order. I felt alone in the situation and it felt absurd having to seek a restraining order against my own child...I felt unable to act, completely frozen, in shock about what was happening to my child - I mean, one time he checked my phone and almost attacked me saying he would kill me if he ever found out again that I had been in contact with the authorities. I was constantly scared. I had to force myself to eat and I got stomach pains and heartburn. I tried to be home as little as possible but.. it was my home. Where should a person escape to from their own home?

One morning, I went to the kitchen and my son was sitting there. His eyes were the size of a plate so I thought oh ok, here we go again. I tried to be as invisible as possible but my son built up a quarrel between us...and he finally insisted that I had promised to give him a lot of money. His behaviour was shameless. I don't remember where I got that sudden strength and courage from but I remember the words I said- it was like someone else spoke through me. I told him that it was shameful that a grown adult like him would exploit his old mother like that and that I had no responsibility whatsoever to fund his lifestyle. *[seems tense, speaking really fast]* He started raging, sweeping all the coffee cups and glasses to the floor.

He said that I had ruined his life and that it was my obligation to pay for what I had done to him. Then he pushed me...and shouted. I looked into his eyes and knew that no words of sense would help me.. I instantly regretted what I had said to him and escaped to the living room. He followed me... started hitting me properly. He pushed me again... I fell badly onto the table corner and I ended up injuring my hand. I suppose the hip broke when I hit the floor. Then I kind of saw myself from the outside and I was just screaming. I have no idea where it came from... but it came from somewhere deep down in me...the pain, the fear, and ... [*looks very sad*] It was like a primitive reaction almost...I thought : this is how everything ends, this is how I will die. I later learned my neighbour had called the police. I remember the horrible pain and the first aiders...the nurses around me seemed very busy and were only focusing on my physical pain. None of them asked what had happened to me and why. Only one nursing assistant who was cleaning my room held my hand and sat next to my bed.. she was so kind. After a week in the hospital a social worker visited. She interviewed me in an efficient and official way but it was surprisingly easy to talk because I knew that things needed to change. I couldn't live like that any more. [*with strong emphasis*] That made me speak. I wanted to get those bad feelings and events I had carried in me, out of me.

When I returned home, I felt really sick and in pain so the social worker arranged a place for me in a rehabilitation home; that's where I heard about the peer support group for people experiencing domestic violence and I knew it was important for me to start building a new chapter. They had to prosecute in this case. The prosecutors made it seem like a clear case and we discussed it in the peer support group but I was quite scared about it and nobody told me how the process would go or what was expected from me. I met my support person and we went to the court together. It was such a relief I had her there for me. It was a frightening moment when my son arrived. He didn't even look at me... I wanted to hug him and ask how he was doing but because of the situation I couldn't. It was all so horrible. Then came the courtroom...[*pauses for a long time*] I felt so anxious...The feeling I got from the prosecutor was that he was annoyed, that it was all my fault, like I was the 100th stupid mother in his queue who was unable to handle her family relations. He asked why such a fuss was being made about such a matter. He said 'You're two reasonable adults, surely you can deal with this yourselves in private and make amends as you see fit?'. My son was quick to agree but I felt betrayed and speechless. The judge seemed more empathetic and asked me several times if I would be OK with settling the case out of court. I was definitely not OK but I was too scared of my son's reaction and the prosecutor's response to say no. I felt so frustrated with the authorities and the help they constantly failed to provide me. Once again, I had my hopes

up but they came crashing down. My son didn't look at me once during the whole time. Not even once. Why would they drag me through the stressful investigation and prosecution process just to send us home again with no consequences or changes to the situation?

After the events, he did move out and there was no more abuse, but his visits home got rare and he would not respond to my calls. I was so distressed. You can't just switch off love. I was very worried about where he was, wondering was he alive at all so once a week I visited the needle-exchange facility, hoping I would see him or there would be someone who could tell me where he was or if he was dead. *(About to cry.. pause)* It's been about six years now. I can't think of anything I could have done differently. I know that what happened with his father and me being a single mum probably caused him to feel insecure at times and maybe my son felt lacking emotionally and the drugs filled that void...but I don't want to or feel I need to blame myself. But surely the authorities should be better trained to identify and take abuse against older people more seriously. Would they have acted differently if I'd been a child? I think they would, although I was also defenceless against my adult son. And older people can have difficulties in putting their experiences and emotions into words, but that does not automatically mean that I am just a silly old lady with too much imagination or memory problems to be taken seriously. We deserve justice and to have our rights respected and to be given the proper support from caring and qualified people.. I've already lost my son, I've lost my physical and emotional health. I've lost enough.

ELSA: *(rises from the bench, she is having a very serious phone conversation, while trying to keep herself calm and together).* You deserve the opportunity to get your case heard. You can't blame yourself Anna...You're a wonderful, caring and efficient professional, and human being for that matter. And I know that now you will blame yourself but I don't blame you. I'll call to see you when I finish my shift.....I promise. See you later. *(She is now centre stage. On finishing the call she breaks down).*

All the other characters are bewildered as to what to do. They look confusingly around to each other, to Elsa and to the audience beseeching them for help. Finally, Tom rises and slowly approaches Elsa. He puts his hand on her shoulder. Elsa is visibly moved by his gesture. Gradually each character approaches offering Elsa comfort and support. In turn the characters address the audience.

TOM: That phone call was any care giver's worst nightmare. Anna, Elsa's colleague and friend sets the scheduling for visits, and accidentally deleted a lady off the visits roster.

Nobody visited her for a week. She was found dead in her home after the error was eventually detected.

ELSA: I promised “No-one would be left behind”.

CHIARA: A poor lady’s passing was because of a human error. The error of an overworked and dedicated care giver. These things shouldn’t happen, but are more likely to happen when there’s way too much work to do and staff are overwhelmed and burnt out. Do you want your mother, grandmother, sister or brother to be that error? Is this the will of the people?

INGRID: Elsa was once empowered by her work and found it so rewarding, but the years of cuts and policies have worn her down. And she has huge fears for her future too. She retires shortly and dreads the possibility of being dependant on a system that is utterly broken.

ELSA: I left her behind.

RUBY: It takes a village to raise a child. Once farmers helped each other to save the harvest. Maybe it takes a village to save an elder.

ELSA: We left her behind (*rising, impassioned and defiant*). It’s not a good time to be an older person right now. Everyone has a monetary value. It’s generally perceived that everyone should be productive and contribute to the public purse. But, there is a fear of death in our society, in our global village. We have cleaned death away from our lives completely. Being old has become an uncomfortable reminder that getting old and dying is also our destiny too. Older people should be taken seriously and given the status and value we deserve. Walk two moons in our shoes and see that we don’t want much...just...

JOAN:to be listened to and not be discriminated against or denied access to health and social care because of my age.

INGRID:to be taken seriously and protected from obvious harm.

TOM: ...to be able to return to work, so that I can provide for myself.

CHIARA:to be safe in my own home.

RUBY:to be valued as human being living with dementia.

ELSA: The wealth and knowledge and skills that we have is an untapped resource for younger generations and society as a whole. We should be lifted up on pedestals to be honoured and not excluded from life and hidden away in homes and institutions. We need and deserve equal status. This loneliness and feeling of exclusion can be devastating. We need to understand as individuals and as a collective that the smaller the circle of life

becomes, the more it needs to be of quality. The whole conversation around aging must change. Often the most brilliant solutions are simple. People's attitudes are shifting. Ordinary people are concerned about the state of our elderly care. This is a new thing. This is a good thing. We are not willing to put up with just anything anymore. Are you? It's time to start demanding actions from politicians. It's time for change. Always remember it is in darkest and deepest winter that spring is born. Our New Winter War begins right here, right now. (*With hope and optimism*) Let's make sure to leave no-one to survive alone. (*All characters in unison*) Let's leave no-one behind.

CURTAIN

Script two:

Our stories: human rights and older people in Europe

Script Two for the play incorporates six monologues linked together by the introduction of an advocate. The performance of the play takes approximately one hour and ten minutes. Each monologue takes approximately 10 minutes to perform and they can be used individually.

ADVOCATE: Ladies and gentlemen, the great day of the vindication has arrived, the great day in which we will deal with that condition of life which is old age, which is very pressing for everyone of us, ordinary mortals. And we will do it in defense of those rights that are universally valid and which recognizes us as "human beings". And here, we have to claim, or rather: insist on claiming. To oppose the injustices of those who too often want to decide for us or ignore us.

The elderly are older persons, not victims! We don't want them to be victims just because they are old. And on the day of the claim we will hear some stories of injustice and trampled respect. There will not be sad complaints to make us say: "poor little men!" On the contrary, these stories should lead us to say: "that's enough! I want, and I can, do something so that this does not happen to my grandfather or my mother, or to people around me in this world where we all should be a little more supportive! "... and to make sure that doesn't happen to me tomorrow!

CHIARA: My doctor thinks that I'm in my 80's, but I'm not, I am 79 years old. My husband passed away four years ago. And now I live alone. My life has been a struggle but there were good times too. Would you believe that I've had thirteen serious operations throughout my life? The only one that ever really worried me was the heart surgery. There was a serious possibility of me dying. But I have always pushed through and survived. (*Contemplating*)

As soon as I got married, I went to live with my in-laws in the country. They were all men, and we looked after each other. They were good to me, and I to them. Human kindness is very important to me. I like to help others. (*Pause*) Here in my apartment building I do my best to get along with everyone. Naturally there are disagreements and heated discussions. If something needs to be said, we say it. It's the best way. Once my TV was stolen, and I knew

who the thief was – it was the lady on the first floor. She hasn't had too much luck in life either. *(Pause)*

There was a time when I was very down and I cried a great deal. My daughters and grandchildren are very good to me, and they helped me get through it. My granddaughter tells me, "No one makes macaroni the way you do, grandma" I adore them. I spend Christmas with them. My friend Vittoria comes too. She has no one. But, she's part of the family now. She's 89 years old and fiercely independent. She likes to do her own thing. If she doesn't get to the cemetery three times a week she goes crazy. I don't feel the same need. I visit my husband's grave on and off. We were married for 50 years. He smoked so much that he burned his lungs out. The doctor told him, so many times, "If you stop you still have a chance. You still have time". He never stopped. *(Pause)* That's life!

But then this bad thing happened. I was heading out to do my shopping when I saw two men coming up the corridor. They informed me, "Madam, we are from the water company, and we need to do a water check." Vittoria was also with me and so I let them come up to check the water pipes. They had badges. They wore normal clothes. One went into the kitchen and my friend stayed with me. Then the other one came up behind me with a photograph of my mom and one of my dad ... and he puts them like this ... one here and one there ... and I said to him: "Excuse me, but how did you get the pictures of my mom and dad? And he told me to "take off my rings. I did everything he asked. All I had left was my wedding ring. All of my rings were stolen from me. And then again, he asked, "Do you have any other gold?" "Yes." I said. I had a bracelet in my drawer that my husband had given to me on my honeymoon. I took it out of the drawer and gave it to him. Then he asked me again: "Do you have any money here?" "Yes. I have four hundred euros." I gave it all to him, as if it were a normal thing! It was like they had hypnotized me. Then as they were leaving, I suppose I snapped out of it, I don't know, I grabbed him by the hand just like that, and I said to him: "A curse on you for robbing me." I remember he had gloves. I grabbed him by the hands like that ... my friend was with me ... and I started screaming ... I went down the stairs or by the elevator, I don't remember ... I just know that I started screaming and all the residents of the building came out and were down stairs. I made gestures, screamed ...Some women shouted: "Let's call the ambulance! ... Let's call the police!" I told the ambulance people when they arrived, "I'm not going to the hospital! If I have to die, I'll die in my house!" In short, the whole episode really destroyed me! In the evenings I say to myself, "Don't think about it! " But when I go to bed, I think about it. "How on earth did I not realise!" But they must have done something to me because I said, "Yes." If I said No they might have beaten me! One had a cap with a visor.

If I saw him again, I would scratch him like a cat! I feel angry! Now when I see things like this on television I say, "Look at how I ended up as well!" Unfortunately, you hear of so many stories like this! What kind of people are they? Taking advantage of the elderly! How can they do that? Steal what little I have. All my life savings gone. It's like stealing an old man's bread. Even animals don't do that. I get so angry sometimes! ... *(Pause)*

Now I'm afraid to leave the house. It's not so bad when I am out and have distractions. It's only when I'm at home and I start thinking: "But why did something like this happen to me?" I shouldn't carry my bag outside, I know, but I do. If I'm here alone at home, I can't stop thinking: How did they do that? ... They could even have beaten me badly! *(Pause, worried)*

Then there is also the man who lives on the ground floor. One day I went down to hang the laundry in the common room with Vittoria and he accused us of being delinquent thieves who robbed him. "What have we stolen from you?", I said in our defence. "My wife's dress." he said wickedly. I was so annoyed that I said, "Me? Your wife's dress? Do you know what I would do with your dress? I would wipe my ass with it!" Then he asked me to hit him. Vittoria kept saying "Chiara come away, come away? Let's get out of here!" And I said: "But why do I have to leave, I haven't done anything wrong?" And with a warning finger he said: "Just try touching me and your life is over!" We left and immediately I phoned the building administrator and let him know how we were threatened and that if anything happened to me, he'd know who to be looking for. Then one day we learned that the man's daughter had died very young and that helped us understand his behaviour and mental state of mind. *(Pause)*

And then there is also that boy from the second floor, who deals drugs. One day I saw him unhinging the main door. "Well, what are you doing with the door?" I asked. "I'm taking it off because it has to be open." he said. "You put the door back where it was before, it must be closed." "No, we have to keep it open" he said. And then on the way to the elevator, he tried to punch me! Fortunately, he missed me. The punch was thrown with such force that it left its impression on the elevator! He wanted that punch to hit me! .. And what did the police do? They told me, "We know he is getting treatment. Just make sure not to get on his nerves... because when he is like that he could kill!" *(Pause)* Now in the evening I don't go out because there are always gangs of boys going up and down the stairs. They come here to get drugs. Unfortunately, life is like that! When my husband was around, we lived it up! But I'm happy to stay here. I want to stay here. It's still my home!

ADVOCATE : How many injustices ... How many dangers in Chiara's life! In her apartment building, in her house, where she now finds herself living alone!

Feeling safe in the world we live in, living your own way, if you don't harm anyone else, is a right ... the right to the integrity of your private life, and it is a right that applies to everyone. It is as good for a girl who wants to go out in the evening in a miniskirt, (without the fear of being raped) as for an elderly woman who wants to go out shopping with her bag (without the fear of it being stolen)

Can we say that we can all ask for this right? Can you say?

Could it be then that it responds to a universal need? And that it responds to a need of every human being? Regardless of the condition and age we are in?

This is why they call them universal human rights.

We all have the right that our things are not touched, we all have the right to try to live our way, respecting everyone, but above all our idea of life, we all have the right to be and continue to be ourselves, and Chiara has that right like everyone else. But Chiara is old, more fragile because of her age, and lives alone, in a difficult situation so has she less rights? Or just less strength to claim them?

Chiara lives in an apartment building that does not protect her, that does not make her feel safe.

But the law, even if human, even if it has been passed as a statutory law, does not live, does not exist without the recognition, of apartment building in this case, or in general, of other people, of society. And the society? ... The other people? We are! All of us. In every place and in every time, it's us! Here, in this case Chiara lacked this recognition so much.

Fortunately, not all apartment buildings are like this! How nice it would be and how humane it would be for someone to knock on the neighbour's door every now and then, especially if they are an older person, if they live alone, and if perhaps we have greeted him just today in the elevator, with eyes downcast, or quickly meeting them on the stairs ...

Is Chiara Stubborn!? Rebel!? Challenging?! Chiara clears her throat, raises her voice. She goes out with the bag and risks being knocked on the ground to snatch it ... maybe Chiara doesn't notice, it's not aware of her condition? Could it be? Or maybe Chiara is aware ... aware of suffering the loss of her dignity ... and she hides! She is ashamed of it; she doesn't want to victimize herself even more. There is pride in her. Much. Stubborn!? Maybe. Rebel!? Maybe.

Or maybe it's the desire, the will, the need, as a woman, to be a human being, to continue living as she has always lived, to continue to be herself. Unfortunately, after what happened,

her life changed. Chiara has been deceived. Things were damaged, and so was the person. A violation of her intrinsic value, her dignity, her being. And now maybe Chiara is a little more ashamed, and thinks she is worth a little less... a little older, a little more alone, a little more vulnerable ... Yes, Chiara feels a little less, which is exactly the opposite of the recognition of dignity.

Isn't dignity the right to have a value? Of feeling worthy? But Chiara does not complain about it, she continues to say that she is happy, that she is well ...

Stubborn!? Maybe. Rebel!? Maybe, Smiling!? Maybe. But behind her smile, isn't it evident, crystal clear, her human pain, her tearing, albeit cheerful, mortification?

RUBY: *(smiling)* I was lucky to have a child. The period of motherhood, school and all the things you do with your children was a real blessing. I was 35 and my husband 40. We bought an old building and turned it into a bed and breakfast. Then I got involved in fighting for the lack of services; for children, for mothers, for everyone. *(Pause)* I also decided to go back to university and while I was studying, I worked in a job that promoted the rights of people with disabilities. *(With strenght and determination)* My God, how many injustices there are for the disabled! ... I fought for them ..for many years! *(Pause)*

However, when I was only sixty years old, I was diagnosed with early Alzheimer's and I immediately realized that I had to fight for my rights just as I had fought for disabled people's rights! Because when you're diagnosed and you don't know where to go, when you come home and you sink into fear and depression!... and there is no one who can give you advice. I gave up my job and all my commitments.. *(In a pressing way)* because I was confused, because I was scared, because I couldn't remember! ... *(Determined)* But I should never have given up my job; I should have said, "Alzheimer's can happen to everyone!" But I didn't! I was afraid to say it, I was ashamed! ... Alzheimer's is not like cancer. If you had cancer, you would talk to your employers and say, "I have cancer" and they would say, "I'm sorry!" but they would help you. If you went and said, "I have Alzheimer's" they would immediately find a way to get rid of you. In fact, as soon as I left work, no one contacted me anymore. They all disappeared! ... *(Silence)*

In the end the doctor told me, or he told my husband, I don't remember, "We have to do something for Ruby, to keep her from falling into depression." I didn't realize it, but he was right. I was completely depressed! ... *(with exasperation)* But what was I supposed to do? The world had collapsed on me! ... *(determined)* Then one day I convinced myself: "Yes, I

have to do something!" I phoned a centre for Alzheimer's disease and I decided: I'm going! I got into the car and drove thirty miles to this centre. But when I got there ... they were all ... I wouldn't say old ... but they all looked ... older than old! ... I went to a nurse for advice. Finally she told me: "There's nothing we can offer you here, Ruby. The only thing I can advise you is ... inform yourself - do your research." I thanked her and left. I sat in the car and cried and cried. I thought: This is my life now?! Is this what life has given me?! I finally found the courage to go home. *(Pause)* Then one day at the hospital I was telling my story to a nurse and she said, "I have a number for you. He is a professor at the University. Call him. He's looking for people for his Alzheimer's research using cognitive therapy." From that moment on, my new life journey began! *(Enthusiastically)* The therapy was absolutely fabulous! It completely changed my life! *(with growing enthusiasm)*... writing. Write everything! Write your day, every single thing you do – all to remain cognitively active! Keep your diary up to date- writing everything is very important! ... And not just writing, but also reading. Read a lot. I read all the newspapers. *(Pause)*.

And I'm lucky, I have the love of my family! *(Pause)* ... But so many families right now are deciding, "Don't tell mum she's got it. Or don't tell Dad he has it!" *(with strength and determination)* But they're wrong! ... Why do you have to lie to your mother and not tell her the truth? If she had diabetes, would you tell her? If she had cancer, would you tell her? ... Of course you would! ... Then why wouldn't you tell her she had Alzheimer's? So you could give her the opportunity to be informed so she could decide for herself, at least for as long as she is able! ... *(with indignation)* And then why should we be sent to a nursing home? ... Why shouldn't we live in our own homes when we have worked so hard? Proper assistance is what we need. Look at the train- Why don't they announce the stops on the train so I know where I am? ... Or at the airport? *(In an ironic tone)* When you ask for assistance at the airport? - the first thing that welcomes you when you get off the plane is ... a nice wheelchair! And then I have to tell him: "No, thanks! I was sitting the whole trip, now I would like to stretch my legs a little! "... Once in an airport a girl gave me a lanyard and I asked her: "What's that?" And she replied, " It's for people with autism or memory problems-you must put it on." I said *(ironically)* "A rope collar... like for dogs! How nice, thanks!" We also don't want special lanes either, just safety when we walk to the gates. *(With relentless determination)* Why should I be treated differently to Mary with multiple sclerosis? Or John with Parkinson's? Or Molly who has nothing? Why should I be different from all these people? *(Pause)*

My husband and I applied for home care and a nurse came who offered us personal care. But we needed help in the kitchen because I often burn myself and I can't do things in the

right order anymore. Sometimes I forget I've left the oven on... The nurse listened and then she left. In the end I received an email. (*Sarcastic*) They offered us half an hour a week for personal care. Exactly what we didn't want! We asked for help in the kitchen. You pay taxes, contribute all your life ... And your rights?-You get a half hour from the welfare system ... (*Ironically*). There are so many difficult things to do, so many problems and my anxiety rises in the fear of forgetting all these things to do. (*With restlessness*) Sometimes I wake up in the middle of the night and I don't remember if my husband is still alive or if he is dead! ... I reach out with a frightened hand to feel if he is ... if he is breathing ... thankfully ... he is still alive! (*Pause*)

And you must never forget the power of attorney, which is like a will. It's distressing, I know, but you have to seek some advice on some things, for when you won't have the mental capacity anymore. (*Determined*) I want to make decisions now about my future medical treatment.. But what if I forget what I've decided? Who will enforce my rights for me? For example, I don't want to be cremated; I want to give my body to science, if science wants it! ... And I wrote that in the power of attorney, so they won't forget it! Even if I do! Worse-off though are those unhappy people who are taken to nursing homes when they could stay at home instead and have assistance, not only from the health system but from others. (*Smiling*) "It takes a village to raise a child!" we used to say. Once farmers helped each other to save the harvest. (*Smiling even more*) Maybe it takes a village to save an elder! This is my new life with Alzheimer's. It is not an easy life, of course... but it is still my life!

ADVOCATE: How scaring ladies and gentlemen! Alzheimer's is so scary. To everyone. It is truly a tough journey. For everyone, the person who is affected and the family members. "Most likely it's Alzheimer's" so usually says the diagnosis. Because, to date, the certain diagnosis can unfortunately only be made post-mortem. And scientific research is still in its infancy. Dementia is only the symptom; it is the effect. Dementia, total dementia, the loss of oneself ... and again, fear. No, I don't want to see, I don't want to know, I don't want to listen! I don't want to think about it. But no. We must talk about it, we must listen, we must try to understand! Ignorance and fear are always the spark and flame to ignite and fuel the powerful engine of discrimination. Of any discrimination. And we, together, will stop it!

Ruby is afraid and doesn't know what she can do and what can happen to her. She also understands that it will scare others, and she is ashamed. she herself quit her job, she self discriminates, even before others do. But Alzheimer is an impacting disease, very impactful,

not only on those who are affected but also on those who are close, also on those who try to protect you. And there is discrimination for the persons with dementia but also for those associated with them, discrimination "by association". That is why information is important. But access to information is difficult. Difficulty of accessing information, activities, structures, the suitable rehabilitation necessary to protect residual abilities as much as possible and enhance those not yet affected. Ruby strongly claims her right to autonomy, at least to all autonomy that she is still able to manage. Ruby is still young, she wants to stay at home, claims the right to continue living as she has chosen, vigorously defends all her possible residual autonomy, wants to decide for herself, as long as she is capable of it, as long as she can... For this reason, Ruby claims that patients must be informed as long as they have the ability to understand. Because they can still decide and organize their future, for when they will no longer be competent to do it. We must give as much autonomy as the person can cope with. Who knows what is the right thing ... and if the patient is alone? What can happen? And perhaps the more alone you are, without protection, the more important and fairer it is to be informed. Who can protect your best interest better than yourself? Who better than you will be able to claim your rights, so important to face this painful path of life?

A closer collaboration between professionals is needed, a safety net!

To strongly protect for everyone, even those who are most alone, the right to easily access information. But accessibility means being able to take myself, even if I am alone, from one place to another where I can access services, specific rehabilitation courses, enhance the skills I have left and try to rehabilitate what I have lost, including the cognitive skills, in order to safeguard one of the rights that most makes me a human being: the right to self-determination. As far and as long as I can, I have the right to decide for myself, by myself. And then it is also our task, as a society, because if some rights give us the dignity of human beings, solidarity is what makes our kind the humankind.

TOM: *(Tom has been reading his paper throughout Elsa's phone call. Looking into the audience and as if answering a question)* I guess you'd like to hear my story. Well the name's Tom and I am a contented 63 year old grandfather to my son's two children. I live alone, and just about manage to survive on a very low pension. I'm awaiting an increase, and how much or when, I still don't know. When I'm gone, I'll leave my home and the little I do have to my wonderful grandchildren. *(Ironically)* But, despite things I'm an optimist, an eternal optimist with a very impulsive streak *(laughing)*.

I am an electrician by trade, and I've worked bare-chested in war torn Iraq in 58 degree heat. It wasn't easy, but I managed to make good money, and like any young man I did a lot of stupid things. I had a full and active life back then. Now I'm out of work and I sit here doing nothing all day long. But, I'm not a lazy man and I desperately want to work. I retired at fifty, but it wasn't my decision. You see I had a stroke at work, and a neurologist said to me "I'm going to make you retire, you haven't a chance of ever working again". That was really upsetting, I never wanted to stop working. I was very confused by his diagnosis – I had a problem using my hand correctly, but otherwise I was absolutely fine. I didn't want to retire. After my stroke I never talked to my employer again. I was so angry at the situation, and at him. In hindsight I was very stupid. I should have claimed compensation because the accident happened at work and I should have pushed for my employment rights to be upheld. But, at the time I didn't think about it.

You know I haven't been on a holiday for years. They used to organise these trips for older people. Now they don't do it anymore. It was the only time I got to go anywhere. We visited parks and forests and loads of old churches – to repent out sins (*laughing*). I'm not a religious man, thank God (*laughing*). I might mention his name from time to time though. I've always wanted to see France. I studied French in school, and I was quite good at it. I'd really like to explore that again, but I can't afford the classes. Wouldn't it be great if they were free, maybe? I would certainly go and learn then. But, it's all about the money. Just a little extra would go a long way and mean so much. Not to buy clothes or anything like that. I wear my partner's dead husband's clothes anyway. May he rest in peace. God bless him. I don't want much just a little extra to pay for French classes. Sure it would keep me off the streets (*laughing*). I'm forever walking, I prefer to walk everywhere. On my stroll today I bought a newspaper to look at the jobs section. Do you know what? As I was reading the advertisements, I thought to myself "Wouldn't I be a perfect employee, because at my age I don't sleep anymore, so I'd be able to work twelve hours a day. I'd be a very productive employee (*laughing*). I really want to work. I want to become a security guard; I've done all the necessary training too. Then I might be able to save some money and help out my grandchildren. I love them very dearly. They know I have no money, so they don't ask me for anything. This breaks my heart. My pension is much lower than normal. But, I'm not complaining about it, if I did I'd get nothing and things could be a whole lot worse.

I never contemplated old age as a young man. I got married to a wonderful woman and we had our son, that was like winning the lottery. But, I didn't know what old age would bring. Looking back I should have saved some money, I could have been more careful. If I didn't

have a stroke, I'd be rich. But, life happens. I don't regret anything, what more could I want? My only wish is that my grandchildren will be healthy and have everything they want in life. I don't want anything for myself anymore. I have a home to sleep in and I get my meals at a social service canteen. It's not much, but it's okay, if I had more, I would help my family. Christmas is an embarrassing time for me. I buy very small presents for my family and put them under their Christmas tree along side the other more expensive presents. This makes me so angry. I feel like a failure. I can offer nothing and have little to give. I feel useless, like a rotten cabbage. It would mean the world to me to be working (*Looking through the job advertisements in the newspaper*) A security guard in a bank? I'd have too many responsibilities. I could work in a Kindergarten, but with so many children, it's way too risky. Maybe a caretaker for an office building? I could do that, couldn't I? (*questioning himself*). I desperately want to work, otherwise I just don't know. I just don't know.

ADVOCATE - And this feeling of being useless ... of not being recognized as a person who counts in himself and not feeling worthy of anything! ... Dignity ... But dignity has many ways to be violated. What does Tom lack? The possibility of bringing gifts to his grandchildren? Being able to travel? Being able to study a language? In short, have more money to satisfy his needs and desires. Yes, but who wouldn't?

Tom has a home, tiny, perhaps not adequate. But he has it. They give him clothes. Starving? No, he eats... at the Soup Kitchen. He lives on charity. And he is forced to ask for help to survive.

The dignity of a person is not only the person's self-worth, dignity also comes from outside, it is the consideration of other people, the consideration that is received from society, from the world,. Not always being forced to ask for help to survive is perhaps a right.

"If I had known what old age is." Tom says "If I had known, if I had understood!" Tom got old early, with an insufficient pension to live, at fifty years, because of an illness that left him incapacitated to work. A hand that didn't work. "You can no longer work, you will have to retire..." And Tom received this information, vital for his future, in a moment of absolute frailty. Tom gambled the rest of his life the very next day after he had a stroke! And the doctor who only says "You can't do anything about it" and doesn't explain, and doesn't make you understand, doesn't offer you anything else. And so, he denies forever your right to private life, to your self-determination, to your ability to choose your future and your life. While also violating your right to health!

And then you feel you are worth less and less, and maybe you get depressed ... Tom would still like to work, above all to do a job that makes him feel useful. It has been set forth that everyone has the right to a job that values what you are (even when you are disabled), and therefore what you would like to enhance of yourself. And all this having guaranteed the primary right, which is that to survive. But Tom did not receive and was unable to ask at the right time for adequate information. He did not understand what he was going to face.

We have all signed forms and cards for a medical practice. Did they explain that form to us? I guess not. Yet, information should always be given, offered, clearly, it should be patiently adapted to your conditions and your cultural tools, so that you can always decide and choose with awareness for yourself. "I do not understand. Could you please explain it to me?" "And with courage again:" I don't understand, will you explain it to me again? "It is our right to understand, their duty to explain.

They hadn't explained anything to Tom.

JOAN: Well, I'll tell you a funny one (*laughing aloud*) I've got fairly bright when it comes to protecting my rights. I find that stubbornness is a great attribute as you get older. Two and a half years ago I had a stroke.....No one told me which part of the brain was affected. Not until a year and a half later did I find out that it was my right side (*indicating the right frontal cortex*) and because of that I could have a false sense of my disability. I could think I was better than I was, and I did. Now I'd be normally arrogant (*laughing*) or whatever you like to call it. But, this was very different, I had a denial of my thing, my disability. They call it an acquired brain injury. I have to say when I was in the stroke unit I got very good service. I got medicated up to the eyeballs (*laughing*). I have a stomach like a cow, nothing upsets it, which is a great asset to have when you go home with a big bag of medicine. Along with that I got two weeks rehab, now when I say rehab I mean physio really – physio with a bed..... After that I was able to walk to a degree, not wonderfully. But, I was on my own, and there was no arrangements to call me back, no follow up to see how I was getting on. To be honest I told them I'd be fine (*laughing*). I badly needed to get out of the hospital, you're up to here (*putting hand up over head*). In the end I had to get in contact with them because I was getting a hip replacement and the crowd doing the operation wanted a letter from my cardiologist. And wait until you hear.....I have actually never attended a cardiologist....., he was a geriatrician, and he told me I would get my life back, but it took me awhile to realise you never get your life back. Anyways, he was a geriatrician, and not a cardiologist at all. The thing I would be worried about is that I know other people who have had strokes and they're not on the big load of medication that I am on. So, who is out there monitoring that? In all fairness

my GP is, and I am lucky that I have a good GP. Now if you're going to take advice from me at all take this; once you get to be forty five or older, set yourself up with a good GP. If you don't like your GP dump them and try around for a new one, do it, because if you can't talk to them at forty you're not going to be able to talk to him if something goes wrong later down the line.....isn't it terrible to think that you were thinking you were under a cardiologist's care for two years, and not knowing you weren't and no one saw fit to tell me. I can remember his voice saying all the right things and he was so very encouraging..... Manners counts for a lot.....not like the other fella in that rehab hospital. I had a call back to his clinic so he could discharge me. But, I wasn't ready to be discharged. So, I went to him and said I'm doing fine only there are two or three things I'll be needing... I need to go back to physio, as I'm dragging my left leg, it's sticking to the floor and getting caught and I'm afraid it will trip me up, and I'm very tired all the time, which is probably from the whole load of medicines that would make you tired anyway, and I told him I was feeling quite depressed. And wait until you hear this, your man (*laughing*), this ole doctor sat back (*moving chair back*), and you know that we were about on the same level (*indicating proximity and height positions*), he never looked at me face to face, he focused on a place there on my breast bone with his eyes down kind of (*long pause, then mimicking*) 'Well WE don't know why some people feel tired after a stroke'... 'WE don't know why some people get depressed after a stroke'. (*Laughing*) I could have figured that one out for myself, right..... I wanted something done about it, but I definitely didn't want to go on something that was going to make me addicted and give me another problem. As if I needed more (*laughing*). Then he sent me on a little trot down the corridor to assess my leg..... (*Mimicking his voice and attitude*) 'Your leg is fine, go back to work'. And I was out like that (*clicking fingers*). Discharged. Imagine, three months after having my stroke. The book was closed on my care. He's some fool of a doctor.

Three days after that visit didn't I fall over my leg that was sticking to the ground and I broke my bloody wrist. So, I rang him and told him I want an apology from you, I don't know who you think you are, as far as I know you are a public servant paid for by our taxes, and if you don't, I'm going to make a fuss. He apologised, not in person, just over the phone...I let it go, but not until after suggesting he should go to the stroke information day run for survivors. They are absolutely brilliant, with all the crucial information you don't get from your own public health service. Anyway I told him you might learn a thing or two about strokes from a patient's point of view because you obviously know nothing about it. Of course he didn't answer to that, so I sent him a letter on that one, but I mean the arrogance of it.

My concentration was a big thing too... I was slipping that way; memory lapses, losing things. I found myself in town forgetting my purse, my phone and all sorts. I was very down and completely defeated in myself, and it wouldn't be like me at all. I thought to myself I need a bit of an assessment, so I went to an acquired brain injury charity service to get it done...they couldn't do anything for me because their cut off point is 65, and I had just turned 65. The thing is, if I had been given this information from the hospital right after the stroke two years ago I would have been 63 and could have had this kind of an assessment done. They never told me that I could have lapses, or what part of the brain was affected. I would have liked if somebody could say because of where your clot happened, these are the possibilities of what might happen. They had the CT scans, and with the advice of an expert, they should have been able to tell me what to expect to some extent and maybe even assess me to see was I gone a bit that way already. Wouldn't you think in rehab they'd offer you that? But, no it was only the physio. From a psychological or a neurological point of view there was nothing, looking back it definitely was necessary. When I had the stroke I fitted in to all the services that were going, but as time went on they moved me into the elderly care sector, and you don't become a priority anymore, so effectively there is no funding for my age group.....it's very unfair because now most people work until they are 68. I'm still waiting to get the hip done. I did have an appointment for that, but they are still waiting for the letter from the cardiologist that I'm not attending (*laughing*).

I'm forever writing letters and emails now. I wrote to the fellow who saw me in Rehab to ask what was the protocol for stroke patients when they were discharged as regards physio. I took it up with the Minister (*laughing*) I'm like a dog with a bone, and I told him, "You have a problem with people on hospital trolleys blocking up your A&E's, let me give you a solution for that - give the likes of me that come out after a stroke access to proper physio, and we won't be falling around the place, and left in a mess. Barbaric!! I'll keep saying it, it's the lack of information...I shouldn't have to be going around looking for it...I should have been told what to expect from the start. I think it's my right to know everything about my own health. If I was unfortunate enough to have had the stroke on the other side of my brain, I could have lost my speech, well that was a blessing anyway that didn't happen 'because I live with a 23 year old and you need to be able to shout at a 23 hear old (*laughing*) could you imagine that..... (*Extended laughing*) I'd have ended up living with me sister....oh Jesus no! I always reckon and this is not a word of a lie....I think it's my stubbornness that helped me to recover so well. I'm a noncompliant type. As I said earlier stubbornness is a great attribute to have when you get older. Now, I'm off to buy stamps.....more letters to write. (*laughing*).

ADVOCATE - A simple concept I would like to point out to you, which is a beautiful concept. In law ... the time of communication between doctor and patient is part of the treatment. Which means that listening is also treatment. And listen now to what Elsa, a very experienced care worker, can tell you to about time.

ELSA: I'm often asked what home care is like today for my older patients, and I am direct with my reply – it's horrible... horrible and very unethical. It wasn't always like that. Back in the 80's when I started my career as a practical nurse the government were putting way more money into the health and social care system. Home care visits were allocated way more time – time to chat with your older clients and do all kind of activities with them. You'd often find yourself baking or listening to music with them and looking at photo albums. It sure wasn't the insane rushing like it is nowadays. People living at home and receiving home care are in a worse physical and mental condition then they were back then. Care work is a demanding job. But, the work used to be rewarding. Older people have so much to give, and the work itself was so much more empowering. Of course I was younger then, but I don't ever remember being so incredibly exhausted by it all. I can tell you for certainty that the depression of the last decades changed the whole system. It was such a shock to society as a whole. As a consequence there was considerably less funding for health and social care, and there were strict boundaries in terms of work practices too, which meant way more clients per day, so the quality of care provided worsened greatly. And it's progressively got worse since. Changes to our work were rapid. The weakest were left to survive alone. The weakest were left behind. I've so many colleagues who are thinking of changing their profession. And I fear greatly for our elderly population if that happens. They see the agony and distress in their patient's eyes, and they in turn are anxious and upset having to leave their clients alone in their homes. They feel powerless to change anything. However, the truth was that it was just a cost cutting exercise to reduce the cost of the social and health care sector bill.

There are so many day to day violations of common dignity and human rights. Gross violations – let me give you a simple example; older people don't get to go out. Cows and prisoners have a guaranteed legal right to go out daily but older people don't. Shocking. Shouldn't self-determination and the right to live life as you see fit be available to everyone? On top of that basic needs were taken away... Diapers were not changed as often and the turning of patients didn't happen as often as it should. This was all as a direct consequence of the cutting of the allocated time for each visit. **THE WEAKEST WERE LEFT TO SURVIVE ALONE.** Do you want me give you an example?... Well, one particular older lady was

accidentally deleted off the visits roster. Nobody visited her for over a week. The lady was found dead in her home when the oversight was finally detected. That's just horrible. Of course it was a human error that resulted in her not been found, but these things will happen when, there's way too much work and people start losing track, when you're burned out, and overworked. Surely, this is not 'The will of the people'. **THE WEAKEST ARE LEFT BEHIND.** There is no such thing as client-centeredness or humanity in our system. It's all about efficiency and productivity. It is a structural issue. We need more employees... more resources of every kind. That's basically all that this is about.

Our clients are seriously vulnerable. They get more vulnerable every year. You see the criteria on which someone is placed in a nursing home or even cared for at home are getting stricter and stricter. There needs to be an immediate threat of death, maybe even several threats. Only then will the process to find a place in a nursing home be started. It's certainly not simple. And it's not so easy either to receive even basic home care nowadays. You must be very weak both mentally and physically before you are entitled to anything. As a consequence, we've found that we are caring for an ever increasing number of people with dementia. For those particular older people, the experience of a stranger coming into their home is very scary and unsettling. And it can be a different person on every visit, because the home care employees change constantly. (*ironically*) Changing of guards! The decision makers and planners are not thinking of the effects on these vulnerable people and refuse to see it from their perspective. As I said before it's all about proficiency and efficiency. Visiting someone sometimes you don't even have the time to even check whether the person has eaten or not. It's really like the Wild West. I'm not exaggerating, you never know what to expect. More often than not you only have time to check the most important, like if they have taken their medicine. It feels absolutely horrible leaving them there, when you see they are so distressed and need much more care, attention and companionship. But, there is no time. (*Throwing her hands in disgust, guilt and despair*) **THE WEAKEST ARE LEFT TO SURVIVE ALONE.**

In some cases there are couples receiving home care. It's a situation where one is the carer for the other. The state encourages them to become carers because it saves resources. And of course, the person wants to take up the role because it's about caring for their dear one. They definitely do not get the support and resources that they need.....and they regularly become exhausted and burned out and when they've reached that point they don't even see that they could be potentially neglecting or abusing their loved one. I remember this lovely older couple. The carer used to tie her husband with dementia up to the heater/radiator

whenever she had to go to town. Fortunately, a care worker happened to visit when the lady was gone and released the poor man. When the wife returned she couldn't understand what the problem was at all. She talked to me at a later point and what she said to me amazed me, "What else should I have done? We had no food and I have no-one to shop for us....should we have starved to death or called the police to visit the supermarket for us?" (*Pausing and shaking her head in disbelief*). It's not a good time to be an older person right now. Everyone has a monetary value. And of course there is the fear of death in our society. We have cleaned death away from our lives completely. Being old has become an uncomfortable reminder that getting old and dying is also our destiny too.

Older people should be taken seriously and given the status and value they deserve. The wealth of knowledge and skills that they have is an untapped resource for younger generations and society as a whole. Older people should be lifted up on pedestals to be honoured and not excluded from life and hidden away in homes and institutions. They need and deserve equal status. The loneliness and feeling of exclusion can be devastating. Seriously, we need to understand as individuals and as a collective that the smaller the circle of life becomes, the more it needs to be of quality. The whole discourse related to ageing must change. Often the most brilliant solutions are simple. People's attitudes are shifting. Regular people seem concerned about the state of elderly care. This is a new thing. This is a good thing. People are not willing to put up with just anything anymore. It's time to start demanding actions from institutions. It's time for change.

ADVOCATE - The lack of time to care for the older persons! ... There cannot be such an inhuman and degrading system. An older person is not an object to care for, but must be subject of a care relationship. And we must repeat it loudly, forcefully and with obstinate determination!

INGRID: It started when he began hanging out with the wrong people, when he got a job as a banker. It changed him; he started abusing alcohol first, then drugs, then me. My own son. I got divorced when I was young; I had to get out, but my 2 boys grew up as happy and nice boys, especially the younger one; he always took care of me and his older brother and was very sensitive...and because of that, what happened later on was a complete shock to me.
[pauses]

You see, at 27, my son started losing grip of his life; he lost his apartment and his wife left him. That's when he returned to live with me... I barely recognised him. He was dependent on drugs so one time he asked me for great deal of money and I didn't give it to him. He got so angry, started throwing things and went to the balcony and threw down a chair. I was so embarrassed and hoped that nobody had seen that. And then he hit me.. and that was the first time I ended up with a black eye.. I didn't tell anyone...I just wore sunglasses to the grocery store and waited for it to heal before going anywhere important. I was just so shocked.. the change in him was so huge. It was like one day it was bright and then suddenly out of the blue everything went pitch black. He didn't even apologise. My son's aggressive behaviour increased and he hit me almost weekly. That's when I thought: I cannot take this anymore. So one day I called the police. When I explained the situation they.. [*pauses for a longer time*] they didn't take me seriously. They said that as a mother I should be able to control my own child and I should just kick him out. It made me so sad and anxious that the police would say this. Another time I called they said I needed to start collecting all the proof I had of the violence and only once I had done that, could I report the crime and seek a restraining order. I felt alone in the situation and it felt absurd having to seek a restraining order against my own child...I felt unable to act, completely frozen, in shock about what was happening to my child - I mean, one time he checked my phone and almost attacked me saying he would kill me if he ever found out again that I had been in contact with the authorities. I was constantly scared. I had to force myself to eat and I got stomach pains and heartburn. I tried to be home as little as possible but.. it was my home. Where should a person escape to from their own home?

One morning, I went to the kitchen and my son was sitting there. His eyes were the size of a plate so I thought oh ok, here we go again. I tried to be as invisible as possible but my son built up a quarrel between us...and he finally insisted that I had promised to give him a lot of money. His behaviour was shameless. I don't remember where I got that sudden strength and courage from but I remember the words I said- it was like someone else spoke through me. I told him that it was shameful that a grown adult like him would exploit his old mother like that and that I had no responsibility whatsoever to fund his lifestyle. [*seems tense, speaking really fast*] He started raging, sweeping all the coffee cups and glasses to the floor. He said that I had ruined his life and that it was my obligation to pay for what I had done to him. Then he pushed me...and shouted. I looked into his eyes and knew that no words of sense would help me.. I instantly regretted what I had said to him and escaped to the living room. He followed me... started hitting me properly. He pushed me again... I fell badly onto

the table corner and I ended up injuring my hand. I suppose the hip broke when I hit the floor. Then I kind of saw myself from the outside and I was just screaming. I have no idea where it came from... but it came from somewhere deep down in me...the pain, the fear, and ... *[looks very sad]* It was like a primitive reaction almost...I thought : this is how everything ends, this is how I will die. I later learned my neighbour had called the police. I remember the horrible pain and the first aiders...the nurses around me seemed very busy and were only focusing on my physical pain. None of them asked what had happened to me and why. Only one nursing assistant who was cleaning my room held my hand and sat next to my bed.. she was so kind. After a week in the hospital a social worker visited. She interviewed me in an efficient and official way but it was surprisingly easy to talk because I knew that things needed to change. I couldn't live like that any more. *[with strong emphasis]* That made me speak. I wanted to get those bad feelings and events I had carried in me, out of me.

When I returned home, I felt really sick and in pain so the social worker arranged a place for me in a rehabilitation home; that's where I heard about the peer support group for people experiencing domestic violence and I knew it was important for me to start building a new chapter. They had to prosecute in this case. The prosecutors made it seem like a clear case and we discussed it in the peer support group but I was quite scared about it and nobody told me how the process would go or what was expected from me. I met my support person and we went to the court together. It was such a relief I had her there for me. It was a frightening moment when my son arrived. He didn't even look at me... I wanted to hug him and ask how he was doing but because of the situation I couldn't. It was all so horrible. Then came the courtroom...*[pauses for a long time]* I felt so anxious...The feeling I got from the prosecutor was that he was annoyed, that it was all my fault, like I was the 100th stupid mother in his queue who was unable to handle her family relations. He asked why such a fuss was being made about such a matter. He said 'You're two reasonable adults, surely you can deal with this yourselves in private and make amends as you see fit?'. My son was quick to agree but I felt betrayed and speechless. The judge seemed more empathetic and asked me several times if I would be OK with settling the case out of court. I was definitely not OK but I was too scared of my son's reaction and the prosecutor's response to say no. I felt so frustrated with the authorities and the help they constantly failed to provide me. Once again, I had my hopes up but they came crashing down. My son didn't look at me once during the whole time. Not even once. Why would they drag me through the stressful investigation and prosecution process just to send us home again with no consequences or changes to the situation?

After the events, he did move out and there was no more abuse, but his visits home got rare and he would not respond to my calls. I was so distressed. You can't just switch off love. I was very worried about where he was, wondering was he alive at all so once a week I visited the needle-exchange facility, hoping I would see him or there would be someone who could tell me where he was or if he was dead. (*About to cry.. pause*) It's been about six years now. I can't think of anything I could have done differently. I know that what happened with his father and me being a single mum probably caused him to feel insecure at times and maybe my son felt lacking emotionally and the drugs filled that void...but I don't want to or feel I need to blame myself. But surely the authorities should be better trained to identify and take abuse against older people more seriously. Would they have acted differently if I'd been a child? I think they would, although I was also defenceless against my adult son. And older people can have difficulties in putting their experiences and emotions into words, but that does not automatically mean that I am just a silly old lady with too much imagination or memory problems to be taken seriously. We deserve justice and to have our rights respected and to be given the proper support from caring and qualified people.. I've already lost my son, I've lost my physical and emotional health. I've lost enough.

ADVOCATE - It is such a terribly painful and significant story that we would not like to say anything more. If not to remind everyone of the great value of old age. Because whoever becomes old can see the concrete and true spectacle of life, dominating it in its totality, so much that they can recognize the absolute possible, contradictory and difficult, beauty of this world.

The stories we told, perhaps also tell us that old age is often a place far from peacefulness, it is a place where we still have to fight, where we still feel frustration and anger and where we are still searching for happiness: as in all other stages of life! Don't discriminate against the older persons. They are no different from us, in the feelings, emotions and also in the way they live their experiences. They are therefore fully entitled, like anyone else and perhaps more than anyone else, to claim a possibility of legal protection: a hope for justice.

And this is it, perhaps, the greatest gift we can leave to our children and grandchildren and every one of us men and women, for when the future will come and find us old!

CURTAIN

