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## From Interview to Transcript to Story: Elucidating the Construction of Journalistic Narrative As Qualitative Research

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## From Interview to Transcript to Story: Elucidating the Construction of Journalistic Narrative As Qualitative Research

### Abstract

There is a call to narrative investigators to be more explicit about their ways of working methodologically, in particular concerning dialogic/performative analysis. The purpose of this study was to examine how journalistic storytelling used as qualitative health research transformed, assembled and sequenced interview into transcripts, scenes, digressions, and other language products. A published story from a socio-narratological study of living with the terminal disease Amyotrophic Lateral Sclerosis was selected. Distribution and sequence of modes of transcription, versions of dialogue, transformation of observation and memory to scenes, and conversion of the researcher's reflection to digression, were identified and calculated. Spots in the story conveying the researcher's imaginations were identified. Three modes of transcription were found. Differences between recorded and published dialogue were demonstrated. The construction of a scene and a digression from notes and transcript was shown. Sequencing of narrative techniques was illustrated. Twenty-two spots of imagination were highlighted. The full, published story itself served as discussion by elucidating how selected parts of interview and context became a story through varying narrative constructions. The highlighted imaginations composed a poetic conclusion resonating the intellectual and bodily experience of the interview.

### Keywords

Dialogic/Performative Analysis, Writing as Method of Inquiry, Narrative Journalism

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## From Interview to Transcript to Story: Elucidating the Construction of Journalistic Narrative as Qualitative Research

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*There is a call to narrative investigators to be more explicit about their ways of working methodologically, in particular concerning dialogic/performative analysis. The purpose of this study was to examine how journalistic storytelling used as qualitative health research transformed, assembled and sequenced interview into transcripts, scenes, digressions, and other language products. A published story from a socio-narratological study of living with the terminal disease Amyotrophic Lateral Sclerosis was selected. Distribution and sequence of modes of transcription, versions of dialogue, transformation of observation and memory to scenes, and conversion of the researcher's reflection to digression, were identified and calculated. Spots in the story conveying the researcher's imaginations were identified. Three modes of transcription were found. Differences between recorded and published dialogue were demonstrated. The construction of a scene and a digression from notes and transcript was shown. Sequencing of narrative techniques was illustrated. Twenty-two spots of imagination were highlighted. The full, published story itself served as discussion by elucidating how selected parts of interview and context became a story through varying narrative constructions. The highlighted imaginations composed a poetic conclusion resonating the intellectual and bodily experience of the interview. Keywords: Dialogic/Performative Analysis, Writing as Method of Inquiry, Narrative Journalism*

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First-hand descriptions of the literal process of transforming interview to construct stories are scarce. Methodological publications lack presentations showing in detail how spoken words and other interview material came to be that particular version of what happened and was there (Chase, 2011; Kramer & Call, 2007). This article is an attempt to demonstrate parts of the process by breaking up building stones of a concrete story, and trace their origin through a re-construction of transformative and transcriptive stages. "Textual openness makes it especially important for investigators to be explicit about their ways of working methodologically..." Riessman (2008, p. 137) made clear in her acclaimed and widely cited methodological textbook on narrative research. In particular, she related the demand to be explicit to dialogic/performative analysis, where the investigator "becomes an active presence in the text" and a "profound importance of context in the construction and performance of narrative" takes place. The research relationship is "an unfolding dialogue that includes the voice of the investigator who speculates openly about the meaning of a participant's utterances," and "the research report becomes a 'story' with readers the audience, shaping meaning by their interpretations." Unlike thematic and structural narrative analysis, "meaning in the dialogic approach does not reside in a speaker's narrative, but in the dialogue between speaker and listener(s), investigator and transcript, and text and reader" (Riessman, 2008, p. 105, pp. 137-139).

I belong to a subculture of journalists who think of themselves as narrative researchers (Harrington, 1997, 2003; Denzin, 1997, 2003). We examine experience by creating a story resonating that experience in the body and mind of a reader (Frank, 2010). I view the narrative

journalistic story as a simple way of producing a text about truth as meaning, and as qualitative research, I suggest the term *true writing analysis* (Jeppesen & Hansen, 2011). A true writing narrative journalistic researcher uses ordinary literary techniques in order to create an account that qualifies as a story, but he must not invent just anything that fits his imagination. He has to stay truthful to reality in the sense that what he represents has actually taken place in verifiable way determined by the audience as the shaping of a meaningful interpretation. The interviewee/speaker and listener/investigator of an interview normally are the first members of this audience. True writing analysis is a non-fictitious story that meets requirements for heterogeneity, sensitivity, transparency, and reflexivity (see Figure 1), resembling what Riessman (2008) categorizes as dialogic/performative analysis.

Figure 1

		True Writing Concepts		
Authenticity Categories		<b>Frank (2004a)</b>	<b>Richardson/St. Pierre (2005)</b>	<b>Denzin (2003)</b>
	<b>Heterogeneity</b>	<i>A sense of the other's inner unfinalizability</i>	<i>How to document becoming</i>	<i>Interviewing another is a privilege granted</i>
	<b>Change</b>	<i>One story calls forth another story</i>	<i>Generate new questions</i>	<i>Take public action on private troubles</i>
	<b>Sensibility</b>	<i>A space of consolation</i>	<i>Affect me emotionally or intellectually</i>	<i>Create moral compassion</i>
	<b>Transparency</b>	<i>A new relation of author to character</i>	<i>The self as knower and teller</i>	<i>Show one's moral colors</i>
Unreliability Categories	<b>Reflexivity</b>	<i>Instigate self reflections</i>	<i>Author's subjectivity both a producer and a product of the text</i>	<i>Reader experiences his own subjectivity</i>
	<b>Emotionalism</b>	<i>Unification with the other</i>	<i>Not demonstrating a social scientific perspective</i>	<i>Confessional mode</i>
	<b>Neutrality</b>	<i>Extracting static themes or listing of characteristics</i>	<i>Boring</i>	<i>Access to a private self, which is the real self</i>
	<b>Superior Knowledge</b>	<i>Monologue</i>	<i>The scientific goal is representation</i>	<i>Certain experiences are more authentic than others</i>

Reference: Jeppesen, J. & Hansen, H.P. (2011). Narrative journalism as complementary inquiry. *Qualitative Studies*, 2(2): 98-117.

Mishler (1991) showed how the relation between representation and reality in transcription of discourse is circumstantial and relying on the author's subjective choices, and narrative analysis, basically, investigates how a writer assembles and sequences events and uses language to communicate meaning (Riessman, 2008, p. 11). The aim of this study was to demonstrate subjective choices in transcription of discourse, and to investigate the assembling and sequencing of events in the form of transcripts, scenes, digressions, and other narrative journalistic language products, to communicate meaning of living with a rapidly progressive and terminal disease. By accounting for the profound reorganization of narrative data that takes place during the construction of a story based on the aesthetic of journalistic narrative and true writing analysis, I wanted to examine "the dialogue between investigator and transcript" with the overriding purpose to meet a demand for textual openness in dialogic/performative analysis.

## Materials and Methods

I selected the story *We won - in parenthesis* from a socio-narratological study of using stories in palliative rehabilitation for people living with amyotrophic lateral sclerosis (ALS) (Jeppesen, 2013a). This story frequently alternates between narrative journalistic techniques and shifts back and forth between time and place of writing, reflection, and interviewing. Therefore, I found it particularly suitable to illuminate the constructivity in generation, assembling, and sequencing language components that transform interview into story.

### Participants

Six people with ALS (3 men, 3 women; aged between 37-63 years) participated in the socio-narratological study. They were recruited through the national rehabilitation centre for neuromuscular diseases with purposeful sampling criteria seeking variation with respect to ability to speak, compliance with clinical rehabilitation norms, educational level, and occupation. Five participants were married with 2-4 children. At inclusion, one participant's speech was incomprehensible, and two participants lost the ability to speak during the study period.

### Interviews

Each participant was visited and interviewed at home four times in the year, with 3-monthly intervals. Part of each visit was a long slow-paced narrative interview conversation, accommodating the ever-changing situation and circumstances dictated by the disease. To accomplish a full interview compensating a deteriorating ability to speak, sufficient time, patience and occasionally the interpretative assistance from a spouse or a professional carer were needed. The level of accommodations varied according to disease progression and/or type of ALS. Concurrently with the interview conversation, the researcher took notes of observations and events (e.g. person's appearance, movements and actions; the weather, the interior decorating, visits from health service professionals, children' and spouses' actions and statements). The researcher's own impressions and reflections were also noted down. The conversation was audio recorded.

### Stories

After each visit and interview, a story was crafted in accordance with criteria of true writing analysis and narrative journalistic storytelling, using verbatim transcripts as monologue or dialogue, scenic descriptions of interview situations, observations of symbolic details, and digressions as author's reflections. Next, the story was sent to a readership chosen by the participant as his or her most significant health professionals. Finally, at the end of the study period the four separate stories with the participant were published on the website of The National Rehabilitation Centre for Neuromuscular Diseases, appearing as one consecutive narrative (Jeppesen, 2013b). A survey about the usefulness of the stories was carried out in the readership of significant health professionals (Jeppesen, Gredal, Rahbek, & Hansen, 2012). Further, a thematic analysis was conducted, showing both the stories' capacity to communicate and continuously normalize anew the individual's everyday life, and to reveal areas of tension in relation to health professionals' perspectives (Jeppesen, Rahbek, Gredal, & Hansen, 2015).

## Transcription

Audio recordings were transcribed in three forms: Transcript, Paraphrase, and Summary. Transcript was verbatim transcription; Paraphrase was abridged and rephrased reproduction of conversation with passages of verbatim transcription; Summary was briefly summarized reproduction of audio recording with a few verbatim quotes.

I listened through the recordings passage for passage. I defined a passage as conversation about a subject that thematically differed from the subject of the preceding and subsequent conversation. After each passage, I chose the form of transcription based on my subjective judgment of that passage's *capacities as presentation of meaning* in a story that already at this point existed in my imagination about what was important and possible to narrate about the meeting, and which I concurrently began to give shape in keywords, draft outlines, working titles, and possible beginnings.

Paraphrase and Summary were as essential for the story as Transcript. Because the judgment of a passage's capacities as presentation of meaning was my capability to sense how the spoken words and utterances of a passage could optimally be narrated as story. To sense in this manner I understood as hearing how the meaning of spoken words and utterances could optimally be represented as monologue, dialogue, scene, observation of symbolic detail, digression, informal speech, or combinations of these narrative journalistic techniques. I excluded passages that I judged unable to present relevant meaning as narrative experience in the story.

## Ethical Approval

Approval for the study was obtained from the Danish state data protection agency and the ethical committee of the national neuromuscular patient association and rehabilitation centre. The participants were informed through an introductory letter explaining the study. Prior to the first interview, written consent was obtained after elaborate information and conversation about study purposes. In addition, ongoing consent was obtained from each participant concerning the production, distribution, and publication of stories, including the use of real names for the website publication.

## Analysis

**Distribution and Sequencing.** Firstly, I calculated the quantitative distribution of Transcript, Paraphrase, and Summary, supplemented by a short résumé of the excluded passages. Secondly, I reproduced the sequencing of Transcript, Paraphrase, and Summary in the chronology of the audio recording, followed by the selection and sequencing of these in the published story.

**Version, Transformation, and Conversion.** Then, I quoted a piece of dialogue in three versions: The published, the one I transcribed, and finally a new verbatim transcription with every single word reported. After that, I exemplified how I transformed notes of observation and memory to a scene and converted a piece of reflective Summary to a digression.

**Narrative Techniques and Imaginations.** Finally, I illustrated the quantitative distribution and sequencing of the story's narrative journalistic techniques, followed by locating and highlighting the spots of subjective authors' imaginations in the published story. Concurrently, the quoting of the full, published story serves as Discussion.

## Findings

### Distribution of Modes of Transcription

The total duration of the audio recording (file 330002.dss) was 1 hour, 43 minutes, and 19 seconds (1:43:19). There were 4 Transcripts equaling 10 minutes in all (Transcript 1 (0:05:03-0:05:37=30 seconds), Transcript 2 (1:04:19-1:05:21=62 seconds), Transcript 3 (1:09:47-1:17:10=443 seconds), Transcript 4 (1:27:37-1:28:42=65 seconds). There were 5 Paraphrases equaling 9 minutes and 55 seconds in all (Paraphrase 1(0:00:29-0:00:40 and 0:00:45-0:00:50=16 seconds), Paraphrase 2 (0:05:44-0:06:19 and 0:06:37-0:07:03=61 seconds), Paraphrase 3 (0:07:08-0:09:08=120 seconds), Paraphrase 4 (0:51:12-0:58.11=419 seconds), Paraphrase 5 (0:58:23-1:04:12=339 seconds). There were 4 Summaries equaling 67 minutes and 47 seconds in all (Summary 1 (0:09:15-0:49:46=2431 seconds), Summary 2 (1:06:12-1:09:45=213 seconds), Summary 3 (1:17:48-1:27:35=587 seconds), Summary 4 (1:29:23-1:43:19=836 seconds). The total duration of Transcripts, Paraphrases, and Summaries was 1 hour, 27 minutes, and 42 seconds. The excluded passages of the audio recording amounted to 15 minutes and 37 seconds, and they featured Tonny Hansen's road guiding instructions, comments to heavy rain showers during a drive, conversation about the soccerclub AGF, and conversation about the soccer player Martin Jørgensen's selection to the world cup in South Africa.

### Sequence of Transcripts

The chronological sequence of Transcript (T), Paraphrase (P), and Summary (S) in the audio recording was P1-T1-P2-P3-S1-P4-P5-T2-S2-T3-S3-T4-S4. The sequence of Transcripts actually used in the published story was S1-P5-T2-T3-P5-T4-P4. Unused transcripts were T1, P1, P2, P3, S2, S3.

### *Versions of dialogue*

The following dialogue in *We won – in parenthesis* came from Transcription 3 (T3). The published version ran:

I wish it could be Tinna. But it can't – and it shouldn't. She has her job. I must admit though that I've been pushing her a bit lately. Asked her if she thinks it's about time she stays more at home. And I actually felt sorry for her. I sensed that she didn't like me asking. I guess I was a bit too selfish – and I know it won't work out.

*So on one hand, you'd like her to try to stay more at home and on the other hand common sense tells you that no, she has to do her job and keep on doing it?*

Yes, because I sense it's what she wants to do. But she's so fucking good at taking care of me. She almost treats me like I was the King of Denmark. She does everything for me.

*Can she do too much for you?*

Mmm... it sometimes feels like she's on the verge of a breakdown. She cries at the drop of a hat.

Transcription 3 (T3) ran:

Tonny Hansen (TH): I wish it could be Tinna. But it can't – and it shouldn't. She has her job.

I must admit though that I've been pushing her a bit lately. Asked her if she thinks it's about time she stays more at home. And I actually felt sorry for her. I sensed that she didn't like me asking. I guess I was a bit too selfish – and I know it won't work out.

Interviewer (I): Then what would you say when it comes down to it? I think on one hand you try to make her stay more at home – and I understand it very well ... but your common sense says: No, she has to do her job and just keep on doing it.

TH: Yes, because I sense it's what she wants to do. But she's so fucking good at taking care of me. She almost treats me like I was the King of Denmark. She does everything for me.

I: Can she do too much for you?

TH: It sometimes feels like she's on the verge of a breakdown. She cries at the drop of a hat.

A new transcript with verbatim reproduction of every single word ran as follows:

Tonny Hansen (TH): Well, I wish it could be Tinna...

Interviewer: (I) ...yes you would, yes...

TH: ...but it is not possible. And it can't be...

I: ...no...

TH: ...she has her job

I: Then what would you say when it comes down to it? Would you then ...er...how would you, er...how would you say it?

TH: Well, I must admit though that I've been pushing her a bit lately. Asked her if she thinks it's about time she stays more at home...

I: ...yes, okay...

TH: ... so I actually felt sorry for her...

I: ...hmm...

TH: ...I sensed that she didn't like me asking...

I: ...yes...

TH:..well, I guess I was a bit too selfish...

I: ...yes...

TH: ...but I know it won't work out.

I: So what you...what would you then say when it comes down to it, because you, I think on one hand you try to make her stay more at home – and I understand it very well ...

TH: ...yes, that's...

I: ...but on the other hand, with your common sense, it says: No, she has to do her job and just keep on doing it.

TH: Yes, because I sense it's what she wants to do. But she's so fucking good at taking care of me. You know, she almost treats me like I was the King of Denmark...

I: ...yes...

TH: ...she does everything for me.

I: Hmm, can she even ... can she do too much for you? In a way.

TH: Hmm... well, it sometimes feels like she's on the verge of a breakdown. She cries at the drop of a hat."

### *Transformation of observation and memory to scene*

The following were verbatim quotes of notes I wrote during and after the interview:

The physiotherapist Søren arrives.

Gets massage on neck, shoulders and back. Jar (pot) "Massage-Creme Sensitive", "Grindsted Physiotherapy & Training", two stylised human bodies stretched out, on grey-blue polo shirt, grey trekking pants.

Tonny pulls off (himself) his T-shirt. Gets massage sitting by the kitchentable. Sits with the elbow resting on the table, and the hand against the forehead. Gets physiotherapy twice a week.

In the story the notes were transformed to the following scenic description:

Before all that, the physical therapist came by to massage Tonny’s shoulders and neck, also at the kitchen table. The second he saw Søren at the door, Tonny slowly began to pull off his T-shirt – even slower than he seemed to want to – then placed his right elbow on the table top and his hand on his forehead as support. Søren began working, his hands glittering with Massage-Creme Sensitive as it said on the jar he had put on the table.

*Conversion of reflection to digression*

The following was a verbatim extract from Summary 1:

Grindsted is a great town. I have always lived here” (sentence that would be suited for a documentary, the way it is said, meditatively looking through the windshield, front and the side.

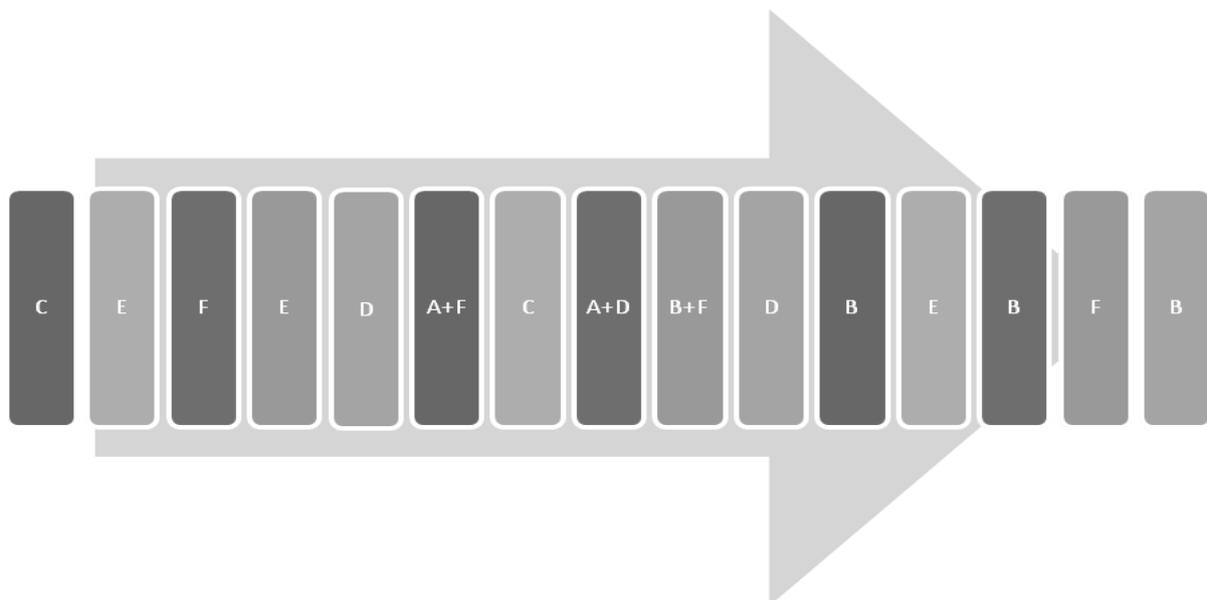
These quotes and notes gave words to the following digression in the story:

We were back in town again and Tonny said, “Grindsted is a great town. I’ve always lived here.” If this were a documentary, the director would pick this cut: Tonny, first looking through the windshield, then the side window, then concluding, “Grindsted is a great town. I’ve always lived here.”

*Narrative journalistic techniques*

Measured by number of lines in the story, the distribution of narrative journalistic techniques were: Monologue (A) 0 %, Dialogue (B) 55 %, Digression (C) 5 %, Observation of symbolic detail (D) 10 %, Informal speech (E) 8 %, Scene (F) 3 %; and combinations A+F 12 %, A+D 4 %, B+F 3 %. Figure 2 illustrates the sequence of journalistic techniques used.

Figure 2. *Sequence of dialogue (B), Digression (C), Observation (D), Informal speech (E), Scene (F), and combinations of Monologue and Scene (A+F), Monologue and Observation of symbolic detail (A+D), and Dialogue and scene (B+F) in the story “We won – in parenthesis”.*



## Discussion

### Imaginations

In the following, I quote the full story, highlighting spots of imagination, i.e. “... passages’ capacities as presentation of meaning...”; “...what was [...] possible to narrate...”; “... my capability to sense how...”; “... hearing how the meaning [...] can be represented...” (See section *Materials and Methods*, paragraph *Transcription*).

Concurrently, the published story itself is a discussion of the quality of both the selection of parts of interview transcription and –context, and the sequencing, versions, transformations, conversions, narrative techniques, and imaginations actually used.

### We Won – in Parenthesis

It has been two weeks since I visited Tonny. Today, we know the results: Denmark lost – first to Holland, in somewhat honorable fashion, only to be drubbed by Japan yesterday. We will put the victory over Cameroun in parentheses.

On Friday, June 11, we met to talk about life with ALS. The talk revolved around Tonny’s thoughts about his past and future and a lot around his relationship with his wife Tinna – plus some football: the destiny of the defeated national team and Tonny’s own exit from the team in Nollund. We drove out there and continued our talk once we had returned to the kitchen table, the pug Bine snoring safely in her spot by the radiator.

Before all that, the physiotherapist came by to massage Tonny’s shoulders and neck, also at the kitchen table. The second he saw Søren at the door, Tonny slowly began to pull off his T-shirt – slower than he seemed to want to – then placed his right elbow on the table top and his hand on his forehead as support. Søren began working, his hands glittering with Massage-Creme Sensitive as it said on the jar he had put on the table.

Twice a week, Søren comes by to give Tony a home treatment because Tonny no longer has the strength to be transported to the clinic.

They talked about the game against the Dutch, which – much to his chagrin – Tonny might not get to watch because he has to go to the hospital on Monday. He is scheduled for a preliminary examination before his stomach tube insertion. He has too many problems with aspiration and consequently does not eat enough – he has gone from 96 to 85 kg – and is afraid of drinking when he is alone. Three times a day, a home health nurse stops by to make sure he gets enough to drink.

The two of them also briefly discussed the composition of their manager teams. Søren did not have any Danes on his team and Tonny had not had a chance to set his final team yet due to computer problems. His son would come over and fix it before the opening game, otherwise it would be too late.

When Søren had helped him back into his T-shirt and left the house, Tonny told me how much he appreciates having physiotherapy at home and how much Søren has helped him with his paperwork for the local authorities, like when he applied for a mobility scooter.

Overgrown football fields by the old school in Nollund. The 50th birthday party at the community centre in Urup. My first girlfriend. Grandpa’s cowshed. When I fell out the window from the second floor.

With my recorder in his lap, Tonny took a trip down memory lane as we drove along narrow, but straight roads in a flat landscape of sandy fields held together by windbreak after windbreak. A few excerpts:

At some point we had three teams out here; three teams of 11 players, more than they had in town.

Then we merged with the football club in Urup. They were all farmers. When they joined us, we moved up to the next series. That was a day of celebration.

Over here is the community center where I celebrated my 50th birthday – not knowing that I had this disease.

This is Eg where I had my first girlfriend. We rode three people on a moped on our way home in the morning. Then we met my dad's sister and her husband who stopped us. "What the hell were we doing?"

A cow crapped all over me; it had diarrhea. I did not go into the stable for a while. You learned to watch out for a raised tail when you walked through the aisle.

I was born and raised there, in the yellow house with the picket fence. We had an apartment upstairs. As a child, I fell out the window from the second floor. Luckily, nothing happened.

We were back in town again and Tonny said, "Grindsted is a great town. I've always lived here." If this were a documentary, the director would pick this cut: Tonny, first looking through the windshield, then the side window, then concluding: "Grindsted is a great town. I've always lived here."

On our way, we passed the cemeteries in Nollund and Urup. Tonny worked at both of them when he was a cemetery gardener. The conversation turned to weeds and Tonny said:

I really can't walk past a weed without pulling it up. People expect a cemetery to be completely weeded. That's why it bugs the crap out of me that I can't do anything in my own garden. My wife keeps it and she works really hard at keeping it nice. She does everything she can to make it look nice so that I'll want to get out there.

*Are you happy about getting out there?*

Absolutely. I sit out there every single day when the sun is out. I do. She's really good at it.

When we had parked, Tonny asked me if I wanted to see the garden.

The book *Rather Die Laughing than Die of ALS* was in the book holder on the kitchen table when I arrived. The author, Arne Lykke Larsen, has so many different assistants that he can't remember their names, Tonny told me.

*Can you relate to his stories?*

Absolutely! But he's such a professor type at a university and much smarter than me."

*But he's not smarter about having ALS?*

No, no. But he travels. And I'm the complete opposite. I feel most comfortable at home. I'm not as outgoing. He sees and does a bunch of things.

*Do you think you're wrong?*

I'm different, but there's nothing wrong about wanting to be at home. And wanting to visit only the closest family and people you know. Of course I feel sorry for my wife. She's the one who suffers. But she needs to do things on her own.

*Why do you feel sorry for her?*

Because she has to be at home all the time.

*But she could do something for herself?*

Yeah, take exercise classes or whatever she wants to do. But she won't. She wants to stay at home with me, she says. What can I do about that?

*Do you think she'd feel guilty if she did something on her own?*

I think so, yes!

*Are you good at pushing her, telling her that you simply don't want her to hang around you all day? That you'll be fine?*

I just think we're two of a kind. Tinna has never done a lot for herself.

They are about to have a big meeting at home, Tonny told me. A number of professionals are coming to discuss his future help.

I wish it could be Tinna. But it can't – and it shouldn't. She has her job. I must admit though that I've been pushing her a bit lately. Asked her if she thinks it's about time she stays more at home. And I actually felt sorry for her. I sensed that she didn't like me asking. I guess I was a bit too selfish – and I know it won't work out.

*So on one hand, you'd like her to try to stay more at home and on the other hand common sense tells you that no, she has to do her job and keep on doing it?*

Yes, because I sense it's what she wants to do. But she's so fucking good at taking care of me. She almost treats me like I was the King of Denmark. She does everything for me.

*Can she do too much for you?*

Hmm... it sometimes feels like she's on the verge of a breakdown. She cries at the drop of a hat.

*Why do you think she reacts like that?*

Last weekend, we were watching my son's twins from Saturday to Sunday. I could feel she had agreed to do it for my sake. They're a handful. They're three years old, and there she is with me and two kids and the dog to take care of. I could tell she was fucking wiped. When they left Sunday at noon she wasn't worth much.

*But isn't there a limit to how much she can do?*

Of course there is.

*I'm thinking that if you had more help during the week, it would give her more energy when you're together?*

You're absolutely right.

*You could almost see it as a gift you're offering her? It's like people think that when they have ALS or some other lethal disease, they have nothing more to give. But in the situation, things being the way they are, you're actually able to offer her something by saying: "I'm giving you time off from me"?*

Yes, but then you have to let them into your home. **You fucking have to.** And how much privacy does that leave you with?" By "them" Tonny means the professional, hired assistants.

*I guess you have to make sure you clearly define what you want them to do and not to do ...*

... you know very well that once I have the ventilator, **we can't sleep together anymore.** She'd never get any sleep. So we'll have to set up another bedroom.

*You might be able to just lie together. You can do that can't you? And sleep in separate rooms. The actual act of sleeping. There are several ways to organize that.*

**The sexual act** is not an issue anymore. I can't put my mind to it. It's like my drive has gone. As in completely. I guess it's something that comes with the disease. It's a big part of your life, though.

*Is it a problem for you and her? Or just for you? What do you think?*

It sucks – of course it does. But it's not something I think about all the time. It's not like she'll get a lot out of being with a man who sounds like he's dying

because it's taking up all his strength. It's really hard work, so no, it definitely won't work.

*So you've decided in advance that you don't feel like it?*

I don't. The home health nurse says I just have to take some Viagra but what good will that do, you have to be able to breathe too, right? Tinna says it doesn't matter though – she loves me no matter what, she says. But you can't stop thinking that all of a sudden **it's over**. Like something's missing and now you've **failed** at that, too.

Tonny told me he **thinks less about suicide** now than he did some months ago. Now, he can talk to other people about his disease without crying. His dose of antidepressants has been raised, and maybe this has helped him become less depressed, he explained.

Something must be working. Or maybe I've just gotten used to the situation. Maybe I'm just accepting it as it is. All I can do is to make the best of it, but it's taken me time to accept that. Because you pity yourself so much.

*But at some point, you begin to get over your self-pity?*

Yes, you do.

*What does self-pity do to you? What's bad about it?*

For one thing, all the people around you have to listen to **the same record over and over again**. A lot of times, the disease is all you can talk about when you're with other people. But I still often think about how I can get myself out of **this mess**. You're in a state of constant mental stress. You're forced to think about it every day. I have to admit that the other day, I thought about going to the Netherlands. The next day I thought that of course I want a ventilator. **It changes a lot.**

### **Conclusion: The Experience**

I conclude by listing the highlighted imaginations to resonate the intellectual and bodily experience of the interview meeting with Tonny Hansen.

**in parenthesis**

**slower than he seemed**

**hands glittering**

**the composition of their manager teams**

**Overgrown football fields**

I celebrated my 50<sup>th</sup> birthday – not knowing

If this were a documentary

if I wanted to

see the garden

*Do you think you're wrong?*

I'm different

like I was the King of Denmark.

*a gift you're offering her?*

You fucking have to

we can't sleep together anymore

The sexual act

it's over

failed

thinks less about suicide

the same record over and over again

this mess

changes a lot

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