

## Writing on the science of Parkinson's for a large readership<sup>1</sup>

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1. Nice to see you all here. I have been asked to share our experience of writing on the science of Parkinson's for a lay readership. Which I will do with pleasure.
2. My talk will consist of 3 parts: a few personal words, a description of the activities of our writing group, and a list of criteria that we try to obey when we write news items.

I got a PhD in physics and ended up as a professor of climate dynamics. As Head of Research at KNMI, the Dutch Met Service, I was deeply involved with communication about climate change.

In 2007 my partner was diagnosed with Parkinson's. She died a year ago. So we jointly went the whole route, from prodromal uncertainty until the debilitating final phase. Together we tried to make the best of it, with some success. This helped me to cope with feelings of sadness and mourning that arise when you witness the slow disintegration of your loved one. In addition cycling helped and music, and support from family and friends. In the end I also found a lot of diversion in studying the scientific literature on Parkinson's disease. I was highly motivated, understanding something was very rewarding, and of course, I was deeply fascinated by the complexity of the disease and the human biology in general. That helped me accept our fate. At a certain moment, in search of sparring partners, I joined the writing group. So that's what brought me here.

3. Let me now tell you a bit more about our writing group. We are a small group consisting of people with Parkinson's and caregivers and we write short news items for the website of the parkinsonvereniging. This year, so far, we have written over 30 items on a broad range of topics, ranging from risk factors to neurobiological processes, and from diagnosis and therapy to social and emotional aspects and gender issues.
4. I will now describe how we work. I find it useful to distinguish three phases: 1. paper selection; 2. study; and 3. writing. I will go into each of these in some detail.
5. I begin with paper selection. There are approximately 1000 new scientific publications on Parkinson's and other parkinsonisms every month. Using Pubmed or google scholar alerts we try to follow this. Every month Masja, with occasional input from writing group members, makes a shortlist of the most interesting articles. We make a selection from this list in an online meeting, using the following criteria: 1. What is the relevance for our readership?; 2. What is the (scientific) news value?; 3. Is the science sound? We also decide who is going to write a first draft.

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6. Then the study phase starts. After reading a summary, I usually have a lot of questions, which force me to read the whole paper, and possibly other papers to which reference is made. Of course I encounter many things that I do not quite understand, but then google and wikipedia are very helpful. Occasionally we contact an expert or one of the authors for further clarification. Once we have a good understanding of the paper we reassess the relevance for our readers. The explainability is also reassessed. Sometimes a paper turns out to be too technical to explain in simple terms. In some cases we decided not to publish after all.
7. After completion of the study phase the writing phase starts. One should not start writing too hastily because it is important to think first. Some self-reflection may be in place. For instance ask yourself “Why do I write?”. Do I want to boost my career? Do I seek more funding? Or do I really want to help people with Parkinson’s and their caregivers with information? If so one may wonder what type of information? Only positive messages and hope? Or whatever is new?

Before you start you should also answer a number of interrelated questions, namely what are key elements of the message that you want to deliver? What wider context do you have to give in order that your lay audience can appreciate the results? And how are you going to frame the message? I will try to clarify what I mean with the help of an example.

8. A paper<sup>2</sup> on the biological mechanisms that makes pesticides harmful contained this key sentence: *Paraquat also increases acetylation of multiple histone residues in SH-SY5Y cells and rat N27 dopaminergic cells, the latter via inhibition of HDAC*. Apparently, they found that paraquat acts on an epigenetic mechanism. Interesting and relevant. But there are many concepts that would have to be explained for a lay readership. So which concepts are you going to use? Epigenetics? Acetylation? Histones? SH-SY5Y cells? N27 dopaminergic cells? In this case I chose to give context by explaining gene expression in general terms without too many details. The narrative or frame would then be that paraquat influences the way genes are expressed.

Actually, I was not too happy with the result because a key finding was the involvement of the enzyme histone deacetylase or HDAC, and I found no easy way of incorporating that in my simplified narrative. How would you deal with this?

9. After this the actual writing can start. Texts should be well-structured, concise, with short and clear sentences. If appropriate you can refer to other sources for justification or further clarification of assertions. And it is important that you write the introduction and conclusion for the widest possible readership.

A last point that deserves attention is the heading. It should be both attractive and correct. I have two examples illustrating this.

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<sup>2</sup> Tsalenchuk M, Gentleman SM, Marzi SJ. Linking environmental risk factors with epigenetic mechanisms in Parkinson's disease. *NPJ Parkinsons Dis*. 2023 Aug 25;9(1):123. <https://www.nature.com/articles/s41531-023-00568-z>

10. The first example is from my own field of expertise, climate change. NRC, a serious Dutch newspaper had this heading. De Britse kust gaat verloren (The British coast is lost) with the addition . . Climate change accelerates coastal erosion . . . Actually, the article was about a small stretch of coastline, which is naturally eroded by local currents. The currents might be somewhat exacerbated by climate change, but this hypothesis lacked any serious substantiation. So, in my opinion this is a very bad heading, because it is misleading.

Interestingly, we don't agree on this in our writing group, because one member of our writing group, present here today, considered it an ingenious heading because it attracts readers. I wonder how you think about this.

11. Another example. In a paper about the role of neuroinflammation and the inflammasome I first had 'Parkinson remmen door het inflammasoom te remmen' (Delay Parkinson's by inflammasome inhibition), but then I decided to replace it by 'Op weg naar een medicijn dat parkinson afremt?' (Towards a drug that slows down Parkinson's?). Still correct, but it might attract more readers, and in still allowed me to describe the role of the inflammasome.

Please note the question mark. One of us suggested to drop it, but I disagreed. What would you do?

12. Two final points: ChatGTP can be helpful, but never rely on Artificial Intelligence. And of course we circulate a draft in the writing group. Comments are then incorporated in a final revision. It may beneficial to go through several cycles of revision. Occasionally we decide not to publish because of scientific flaws and or a presumed lack of relevance for our readers.

13. I will end now by giving a summary of the criteria that we found useful. You will also find them on the printout, for later reference. They follow more or less from what I have discussed so far. Here they come

- Is the heading attractive and correct?
- Is the text well-structured, concise, are sentences not too long?
- Are key concepts well explained?
- Does it give context, uncertainties and perspective?
- Are justifying/clarifying links given?
- Is the text, and in particular introduction and conclusion, understandable for a wide readership?
- If applicable: what is the added-value of the graphics?

14. Any questions or comments? What about the questions I have raised (Why do I write? How to deal with technical terms? Headings: clickbait or correct?).