

Parkinson's Challenges

176 Progressive disorder of the nervous system with the following difficulties: 1) Walking 2) Tremors 3) Bradykinesia (lack of spontaneous activity) 4) Balance 5) Depression 6) Motor skill loss 7) Handwriting 8) Voice and speech difficulties 9) Memory loss 10) Skin Disorder It starts gradually with subtle signs but then develops into significant difficulties with both gross and fine motor difficulties Affects all areas of ones life All of the above pose a challenge for both the pupil and the teacher

177 None as an Alexander Teacher

178 I have only worked with two people with Parkinsons. They were both a pleasure to work with. One was functioning very well and had only been diagnosed recently - she was still holding down a responsible job and living independently. The other was wheelchair bound and had lost his job. He was very disabled by the condition, he couldn't do basic functions and had had lots Alexander Technique lessons with a previous teacher. He was a big fan of the Technique for alleviating his symptoms and for generally improving his wellbeing.

180 The main challenge, and of course not unique to people with Parkinson's, was that the illness had inevitable symptoms that could not change.

181 REMEMBERING to give a proper Alex Tech lesson and not just focus on the less functioning limbs.

182 I've only worked once with someone so not much to report

186 Time needed to reduce tone at the beginning of the session. Small triggers can increase tone. Even a change of task.

187 The pull-down in front torso, the neck contracting to counteract this; the held tensions in the arm and leg of the side that is most shaky.

189 The students I've had were all in the early stages. They could still drive, work, some were still jogging,etc. Although it can be startling to feel/see them shaking, the hardest thing is to witness the personal devastation or hardship they are facing. I would not call that a challenge exactly, but it can be intense.

190 The stiffness that sets in.. The conviction that nothing can help their condition.

191 No experience

192 My only experience of Parkinson's is through the husband of a friend; he has since died.

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193 They find it difficult to release tension because they have a fear of falling, so they tend to stand rigidly and move in the same way. Their sense of balance is impaired.

195 My husband has Parkinson's, so there are all the challenges of working on one's spouse! Parkinson's is a disease of motivation too, so there are always potential difficulties in engaging with anything that might be helpful - maybe especially AT as one is a pupil and needs to take responsibility for learning; but the same applies to not just AT, but also physiotherapy, speech therapy, dietary changes etc.

196 Getting them not to worry about the tremor.

199 The anxiety and frustration of the pupils. Most of us can quell a little anxiety at a new situation, a person with Parkinson's finds this much more difficult. Trying to give a little Hope without raising expectations unduly. With my principal pupil, I invited his wife to attend lessons. It would have been cruel not to have done but the early lesson were made more difficult thereby. Later lessons were good and there were to people to remember and observe between lessons.

201 I think one of the main challenges is the mental effect of teaching someone with this disease. It is so very important for me to focus on the whole person and not be waylaid by his condition. The basics of AT Supply me with the knowledge that benefits my pupil. Maintaining "up" "open" "light" instructions counteract the curling down rigidity, while work on walking helps reduce the planting on the spot, I could go on.....

203 LONDON It depended on how disabled they were and if the mainly had trembling or stiffness. I only worked with people in a setting of elderly people and without the possibility of proper continuation and follow-on. I also worked with a patient as part of a service offered to people with different disabilities. Again it was not possible to ensure that the lessons were regular.

205 Replacing disbelief and hope with the delight of positive benefit

207 Teacher flexibility around expectations of pupil's ability to 'relax' and what this may look/feel like. There appears to be more stiffness and this may be perceived as tension that is within conscious control. The experience to me is quite different to someone without Parkinson's and the way their body feels when they do not interfere with my movements whilst, say, moving an arm.

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208 With my father it was difficult to convince him that he can effect to the conditions of his life/moving/functioning himself. I got support from the nurses, too. At some poin father got too much medication (dopamine) and he lived two different moments of life at the same time in the 50's and 2008. My students father only came for one lesson and he fell asleep on the table work. More letting go than learning to do something in a new way. Anyhaw. it looked like the bloodcirculation was stronger in the head area after that work (cheecks and ears became red). He is living over 200 km away from our school but my student is studying to become an AT-teacher and we go through some ideas to work with his father. At least he has started to lie down daily.

211 A big challenge, as so often with AT, is not having enough time with them. In an ideal world (!) Parkinson patients would have easy and fairly constant access to AT teachers! It was challenging to get my pupil to work on things when I wasn't there, as she had already so much on her plate.

213 The main challenge in working with pupils with Parkinson are as follows: 1) If they look at the Alexander Technique as a therapy and want to be fixed as opposed to a learning method they will not make good students. The Alexander Technique exists in the field of education with some therapeutic benefits. It does not exist in the "field of therapy" with "educational benefits". Alexander Teachers who do not understand this are not well trained. Sadly there are a lot of A.T. Teachers who fall into this category. 2) If the student with Parkinson's does not have a strong will and wish to change nothing will happen of benefit. 3) If the student with Parkinson's is wallowing in self-pity...feeling sorry for themselves that "life has dealt them a bad hand"...this excessive self-absorbed unhappiness over one's own troubles will not allow them to learn and change. 4) The student with Parkinson's needs to have the financial resources to have more that one Alexander Lesson per week (preferably 3 or more). Also, they need money to pay for the best medical resources that exist and the best therapy that exists (obviously outside of the psychophysical benefits of the Alexander Technique). 5) The Alexander Teacher who works with the Parkinson's student needs to have the experience and teaching skill to connect and create a positive learning atmosphere that works. 6) Above all the Parkinson's student needs a constructive and curious attitude towards life.

216 It was a long time ago that I worked with one pupil with Parkinson's so recollection is not clear. I think the main thing was to do with managing fluctuating energy and application levels.ma

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221 I worked with two Pupils with PD. 1. Pupil in advanced stage, male, about 66. Balance Books had to be replaced by a huge pile of cushions for semi-supine - the curvature and rigidity of the upper spine made books impossible. Release was slow, but we did achieve some freedom in that area. Rigidity - giving enough time for release. This was important, not just for the neck and back, but for the legs, too. It was really worth taking the time. 2. Pupil who had recently been diagnosed. Female. about 50. This pupil also had a fear of being touched - especially head (migraine sufferer). I worked with hands off for the first couple of lessons, and introduced minimal hand guidance very gradually. To the pupil's surprise, after about four or five lessons, she was happy with hands! Her fear of being ruled by the illness was the other challenge - to give her some sense of control. For me, one of the biggest challenges is with the 2nd pupil in particular: I would love to hear how she is getting on. I would love to hear whether she still benefits from the work we were doing. But I don't know how to approach her, without appearing pushy. I would love to know whether she carried on with lessons - with another teacher, maybe. Of course, some of this has to do with my own sense of inadequacy - yet I know that she benefitted.

224 I have no experience of working with Parkinson's except that my mother had Parkinson's for many years before she died. I was sure that she would benefit from classes but she would never cooperate with me. She was a conservative woman and it was too odd for her to have her son moving her around in the AT way. She did, however, finally agree to have lessons with another teacher but after two lessons refused to continue. I think that there were three main problems: 1. her hostility to anything not strictly medical; 2. the over-eagerness of the teacher to overcome her hostility, which resulted in my mother thinking that she was being handled roughly and against her will; 3. her stubbornness and being convinced that her problem was progressive and nothing could improve or alleviate it.

227 Quietening to allow Ease and Movement

228 I'm afraid it was around 26 years ago and I was very inexperienced teacher, and had no idea of how to address working with someone afflicted with Parkinson's. However it turned out to be a positive experience for both of us - it has been my only pupil with Parkinson's.

232 (based on a single experience) Helping the pupil to make lasting changes, which would have involved applying inhibition to deep seated behavioural patterns. I sensed an unwillingness to change at a level that would have involved a different way of relating to others. The pupil was not able to put his health/well being first, consideration for others was the priority even if it made his symptoms worse.

233 Their poor balance leads to bodies that are so fixed and held and they fight to stay upright. One of my pupils was very stooped so had very little peripheral vision and his uncontrollable shaking would occasionally mean we had to curtail the lesson.

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234 I have a very limited experience of this - two pupils only. One, quite advanced, just enjoyed being visited and chatting. The other, it is early days, three lessons so far. A tricky personality, known to me socially, full of excuses, in denial, but responded in the third lesson. However, she has postponed the start of lessons after Christmas. She likes to have things 'sorted' i.e. 'Fixed'. She is not keen on taking on responsibility for herself, just want some it to go away. I gave a chat about AT to the local Parkinson's group some years ago. The chat went well but not a single person contacted me. The organiser of the chat did come for some lessons last year for herself, not an easy pupil, not happy to change anything about herself basically.

235 You have to be more flexible about what you expect from the AT and be realistic. You have to be informed about the illness, as my father suffered from PD I was pretty well informed.

236 Freezing Ability to get on/off the table Number of sessions needed

237 Crowborough

239 Being aware of support needed when getting on/off table and of additional support for legs etc when lying in semi supine.

240 Their general lack of self-confidence and their extreme stiffness which led to very unstable movement which in turn added to their alarm - a very vicious circle.

243 Managing the expectations of care givers.

244 1. Getting them to focus on what they can do, and then to explore the interface around what they can almost do or can intermittently achieve. 2. Tablework to reorganise/release the deeply buried patterns of distortion from Parkinson's. 3. Meditation centering on body awareness and spatial awareness within the body.

245 I have only had one and it was finding a way in to him believing that he cd change and it we help

246 I was asked to do a session on Alexander technique by the organiser of a local Parkinson's Disease group. The organiser had had a very positive experience with individual AT lessons (with another teacher). The group were a little hard to engage - my sense was that they weren't that interested and I failed to persuade them of the benefits despite my best efforts.

248 Changing the view that they are there of a treatment for the condition.

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249 Challenges have changed as I've gained more experience as a teacher, but for the most part, it is my reaction to feelings that I'm not going to be able to help the person. Even if I do help during the lesson, I feel sad that it is not going to change the course of the disease, but only give them some strategies and short-term relief. However, the student can be very happy with even short-term relief. One of the first persons I worked with arrived without having taken medication, thinking it would be better to show me the magnitude of the condition. I was a fairly new teacher, and that experience was overwhelming. Many people with PD lose the ability for facial expression (masking). The feedback I'm used to getting through observation is diminished, so I have to rely on the other cues as I communicate and observe. People with Parkinson's may also mumble or speak very softly, so that is another source of communication that gets altered. Many people with PD experience freezing--they cannot take the next step. It is complicated to teach how to stop mentally and wait and differentiate that from freezing. Improvements through a lesson may not appear at all in the next lesson. It can be a bit like the film Groundhog Day, in that the same lesson is taught and learned, over and over. Another big challenge that I'm aware of, but that I haven't experienced with any students I've had longer term, is that many programs that support Parkinson's encourage big and loud movements and vocalization in a way that is antithetical to the Alexander Technique approach. That sets up oppositions similar to those a teacher might encounter when any student is attached to continuing certain physical exercises that tighten and shorten.

252 My pupil found it challenging to remember the Alexander guiding orders so I emailed him a poster with the words. This particular pupil first attended a group class and then got his diagnosis. His neck was one of the tightest I have ever come across and there seemed to be a lot of fear trapped inside, especially in his stomach. In my opinion as with many conditions, it is an extreme form of the startle reflex pattern. I felt my job was to enable him out of this pattern as best we could.

256 Maybe because of the Dopamine deficiency (no reward hormones) there was a problem for the dear souls who are sick with Parkinson's to practice regularly, the concept of daily practice seemed to be distant to some of them particularly the older ones. But this also could be a negative mind-set but which we noticed in many of these people. Some of the patients lacked a sufficient sense of self worth and we observed a tendency to an attitude of being a victim. As we have training in other areas of psycho-physical health and development we could observe clearly the symptoms of early childhood trauma in almost every one.

257 I have experience of working with Multiple Sclerosis (diagnosed with same 1978). There are many similarities to Parkinson's. I see the main challenge as negativity surrounding diagnosis and temptation to believe nothing can be done to improve situation. Please refer to website 'My Story' for further detail.

258 Limited movement and tremors

260 Adopting to their speed and not being overwhelmed by the disease.

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Parkinson's Challenges

- 261 The anxiety about falling over. The health difficulties that meant cancelling lessons. The need to gain their trust to 'try something new'.
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- 262 Making sure there was a good balance of things in a lesson to not get pupil too tired. Information on progressing lessons.
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- 264 I have only worked with two people with Parkinson's one some years ago. He came on recommendation of his wife who is a nurse. He was in the very early stages newly diagnosed so no very obvious physical manifestation. The challenge was as always with a person who has been persuaded by someone else and not self-referred. He only lasted a few lessons and my feeling was that he couldn't see the point or the effect it might have at this early stage. The second person was again in early stages and did come for around 10 lessons. She did see the benefits and it certainly helped with the tremors, particularly when I had my hands on. She unfortunately could no longer afford lessons. I bumped into her recently and she has deteriorated a lot and become much less mobile. So I guess the challenge here is AT being freely available for people with severe health problems who can no longer work. I assume you have read the research done by Chloe Stallibrass in conjunction with the Parkinson's Society
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- 266 1. I had no training or experience of working with Parkinson's disease therefore it was also an extreme learning curve for me. 2. More than one lesson a week is required because progress is extremely slow.
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- 268 Frequency of lessons and travelling distance. Also the type of medication used to treat Parkinson's has side effects that can create an extra 'layer' of reaction in the system which can make directing a challenge. Not being part of the orthodox support team and wondering what kind of advice and exercise plans are being advised.
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- 270 They varied - cognitive issues for some, including dementia - walking issues and pain for others. Unwillingness to believe that the AT could be helpful as it wasn't prescribed by an MD.
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- 271 The usual challenges of working with elderly people, plus the fact that they clearly had symptoms which were not going away such as a shaking arm.
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- 273 Concern that I would be unable to help, self doubt. The lady came for 6 lessons only, it was early stages

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- 274 No previous instructionso winging it basically. The enormous fear that comes with the disease because of the sometimes sudden changes in mobility, this is not something that is so obvious in pupils without Parkinson's. I found this very challengingback pain I could indentify with but not a clue about what it must be like to live with such a debilitating situation. To take an arm and find it completely rigid , and the person not really be aware of the rigidity is really difficult to understand. Not feeling equippedno map to follow. Making it up as you go alongnot a great recipe for feeling your making a positive contribution to their life.
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- 277 Getting them on and off the table. Not wearing them out. Responding to the varying levels of ability, depend on whether the pupil was having a good or bad day, which varied from lesson to lesson.
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- 279 My main difficulty was a lack of experience in working in this context. It was quite a different experience and I was not sure how to go about making it work!! I worked once with a client as an AT teacher and once as a shaw method teacher (2 separate people) . I think I fell into a little bit of a trap by not wanting to appear ignorant of the situation and so not really asking a lot of questions but in reality being very ignorant of the problems faced by people with Parkinson's and a need to ask lots questions!! So I wanted to appear professional but maybe did the clients a bit of a disservice in the lessons they got.
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- 280 I worked with an elderly lady with Parkinsons many years ago. I seem to remember that she was very wobbly and was afraid of falling over. I remember that she had suffered a few falls prior to taking lessons. The challenge was encouraging her to let go of expectations and open to new possibilities. She responded extremely well.
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- 281 The person I have worked with most has had difficulty in keeping her eyes open during lessons, not just on the table. She even closes her eyes in the street sometimes.

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282 I have had success working with Parkinsons people. I trained in a 4-year, 2,500 hour, Macdonald-like training course -- but I don't do traditional hands-on work (and I don't work in groups). Maybe you have seen some of my writings in Statnews. I believe that the dominant source of mis-use lies in the fact that, from a very young age, every one in Western culture loses connection with how the downward movement of our body mass impacts our motor coordination. We lose this connection -- a connection that was very much alive for us as infants and toddlers -- by the deep, societal conditioning that teaches us that sitting back into chairs, sofas, etc. is perfectly OK. It isn't! Throwing the center of body mass BACKWARDS is a habit taken on subconsciously. We don't do it by choice. Never did. As children, we simply followed our elders and never gave it a second thought. This traps us in what F.M. Alexander called "faulty sensory appreciation" and leaves us with no choice but to "end-gain" our uprightness. This, of course, everybody can do. But to upright with an optimal "means-whereby" requires the straight-down impact of our body mass. This, falling straight down, is something we have 'forgotten' how to do. We haven't done it in a long time. My teaching is about helping students to regain the awareness of the relationship between 'how we go down' and 'how we go up.' The connection is profound, and is a decisive influence on our use in all sitting, standing and locomotive activities. This is particularly important for people with Parkinsons' disease. About a year ago, I was invited to participate in an online 'radio' show at a website (parkinsonsrecovery.com) dedicated to supplying information about Parkinson's disease. I submitted a written article with images to accompany the audio. The article can be accessed at www.uprighting.com/parkinsons.pdf

287 I recently gave one lesson to a man with Parkinson's who lives very close but spends half the year in Portugal. When he is here he intends to have a lesson every day with me.

289 Persuading students to have faith in AT practice of organized thinking. A positive challenge has been to observe students' own "tricks" for initiating motion and build on that in a more explicit AT conceptual way. Harder to teach folk who are grieving/coming to terms with the shock of a relatively new diagnosis. Some PD folk do better staying away from PD support groups because group energy can ve so down in AT AT terms.

290 Access to my teaching studio - the gravel footpath (which is soon to be replaced) is not helpful.

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291 Persuading them that they could have some control over what they experienced. Example: lady came to me one week almost unable to move her wrists and hands. I was surprised as a couple of weeks earlier she had plenty of movement. As we worked with releasing the hands and wrists she allowed the movement to come back and by the end of our hour the pain had gone and she had free movement again. Then she told me she had seen her consultant the week before and had been told that the next stage in the progression of her (disease? Unsure which word was used) she would lose movement in her wrists and hands. She made that happen quite quickly! The stiffness never did come back - she consciously changed her focus to keep them free.

292 I have worked with only 3 individuals that have Parkinson and the application of direction for the individuals was extremely difficult in all cases, except one. What they enjoyed the most was table work and the after lesson effect of feeling much lighter and free. On one particular case the individual had gone through a rare surgery . At the time he was already wheel chair bound and unable to speak. the surgery consisted of connecting a small computerized machine from his heart to his brain . He regained his ability to walk and to speak. He come for few lesson in the technique only 4 as he then left to travel to India to spend the winter in Goa singing with his guitar in hotel on the island. He enjoyed the lessons and if continuing would have been possible i'm sure the improvement would have been great.

293 The huge variation in each individuals ability depending on their stage of Parkinson's. Also, dealing with moments when a pupil gets 'stuck' during a lesson.

294 Movement, flexibility and state of mind

295 New pupil just had 4 lessons. Difficult and rather alarming at first to work with such strong muscle spasms, much pain in hips, table work particularly tricky as so much leg muscle contraction. Monkey seems to work better, but its early days to comment much.

297 Initially thinking of how to apply the technique

299 I have had a pupil who was not diagnosed until a number of lessons were had, after that the pupil left, so I didn't have the opportunity to work on with them.

300 Giving them confidence to trust their new awareness as they learn to direct.

304 Lack of flexibility, limited movement neck, arms and legs.

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- 309 I have only had one pupil with Parkinson's. She came for many lessons and the main challenge was that she didn't like the loss of control of her arm and therefore wanted to hang on to it and didn't want to lie down at all
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- 312 In early stages, they were just like any other pupil. In later stages, they were far more challenging; one fell asleep immediately on the table, rigid muscles caused problems in another. Psychologically unable to focus.
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- 315 Not knowing what to expect. Very advanced symptoms which meant one pupil could not speak at all, and one with extreme dystonia who was so stiff he could not relax at all.
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- 317 Extreme muscular tension, heaviness, lack of motor co-ordination, desire to 'control' the tremors (if they had them) impatience, depression
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- 318 The main challenge with any disability, syndrome or condition is that the pupils never come for enough lessons. They have a few and then stop, so one can never see the project through to find out what the results actually are.
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- 319 Not sure I understand the question. Their challenges were mostly stiffness and some shaking. Sometimes a weakness in the muscles. My challenge was no different from teaching anyone else. Trying to get across the importance of non-doing etc.
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- 320 I only have experience with one man. My pupil had been an RAF pilot, ejected from his jet, parachute failed, in Korea, he nearly died of his multiple injuries, breaking almost every bone. His rehab took a long time, in Korea, Japan and Stoke Mandeville. He came to me late in life, with Parkinson's. A most unusual and rewarding pupil whose problems were many, and not necessarily associated with the Parkinson's so he's probably not a great example for you as his body was as much affected by past injuries as by the disease. In him the rigidity from the Parkinson's was worse than the tremors.
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- 321 The pupil was very heavy and unsteady so it was difficult to work with him in the normal way as I was unable to support him adequately if he lost his balance. I believe depression was a factor also as it was harder for him to access the experience of lightness and release that many pupils do with AT and motivation was lacking.

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