

CASE STUDY 5: SEBASTIAN

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Patient profile

Sebastian is a 27-year-old male who was referred for the Ketogenic Diet (KD) by his Neurologist, on his and his family's request. Sebastian was diagnosed with Lennox-Gastaut Syndrome associated with epilepsy, learning difficulties, ataxia and hypothyroidism. Sebastian has had long standing seizures from the age of 4-years-old. Sebastian was prescribed Clobazam, Leviteracetam, Perampanel, Epilim, Phenytoin and Buccolam. Sebastian started the KD when he was 23-years-old.

Background

Sebastian was having 5-15 seizures/month in the form of generalised seizures and myoclonic jerks. Sebastian's seizures were mainly nocturnal or on waking, usually lasting between 2-3 minutes. Sebastian would experience long recovery times usually 1.5-2 hours.

Sebastian lives in supported accommodation in the community. Sebastian has a PEG which was inserted 18 months prior to his KDT appointment. Sebastian's PEG feed was providing his sole source of nutrition and hydration.

Clinical Assessment

On referral, Sebastian's weight on referral was 59.9 kg and height 1.74 m, with a BMI of 19.7 kg/m^2. Sebastian had been weight stable since his PEG had been inserted.

Sebastian is nil by mouth, with a 15Fr Freka PEG in situ, inserted on 26/05/18. Sebastian was on a bolus feed regimen of standard feeds including Fortisip Compact Fibre, Calogen extra and Fortisip Compact. Sebastian would have 6 bolus feeds a day which provided 2200kcal, CHO 204.7 g (37%), Fat 115.5 g (47%), Prot 76.2 g (14%), Fluid ~2050 ml from feed regime + additional fluid for meds.

Dietetic Intervention

Engagement of staff was key to initiating and monitoring KD in the community. This included the support staff at the home, community dietetics, Neurology team and Sebastian's G.P. The Neurologist and Neurology CNS were contacted to ensure all Sebastian's medications contained the minimal amounts of carbohydrates, for example phenytoin liquid was switched phenytoin capsules. Sebastian's support workers were trained on blood glucose and blood ketone measurements. Protocols were agreed with support staff including management of hypoglycaemia and hyperketosis.

Sebastian was weaned on to the KD across 7 days to mitigate gastrointestinal symptoms.

- On day 1 and 2, 50% of bolus feeds (3 out of 6 feeds) were ketogenic. The remaining bolus feeds were standard feed. The ratio equated to 1.8:1.
- On day 3, 4, 5 66% of bolus feeds (4 out of 6 feeds) were ketogenic. The remaining bolus feeds were standard feed. The ratio equated to 2.2:1.
- On day 6, 83% of bolus feeds (5 out of 6 feeds) were ketogenic. The remaining bolus feeds were standard feed. The ratio equated to 2.5:1.
- On day 7, achieved his target regimen with a ratio of 2.8:1.

Sebastian tolerated initiation of the ketogenic diet well with no reports of nausea or diarrhoea. Blood ketone levels were checked twice daily whilst weaning on to the KD.

Target regimen:

Feed Product	Amount	Fat (g)	CHO (g)	Fibre (g)	Protein (g)	Kcal
Ketocal 4:1 LQ	1000ml (5 cartons)	148	6.1	11.2	30.9	1500 kcal
Prosource TF	135 ml (3 sachets)	0	3		33	132 kcal
Calogen	120 ml	60	0.3	-	-	540 kcal
Optifibre	15 g (3 scoop)	-	0.9	12.9	<0.225	30 kcal
	TOTAL	**208**	**10.3**	**24.1**	**64**	**2202 kcal**

PEG feeding regimen:

6 boluses per day:

3 x (Ketocal 4:1LQ + Prosource TF + 1 scoop Optifibre)

2 x (Ketocal 4:1LQ + 40m l Calogen - neutral)

1 x Calogen - neutral (40ml)

Water flushes: Made up with 2 sachets of Dioralyte mixed in.

Fluid ~2055 ml/day

Learning Points

Using Ketocal 4:1 LQ helped facilitate meeting the dietetic goals. Ketocal 4:1 LQ provided an easy and low burden alternative for support staff to facilitate transition when titrating to the KD. Sebastian has seen an improvement in his seizure frequency and recovery time since remaining on the KD.

Outcome

After Sebastian's 3 month trial, Sebastian reported noticeable differences in his energy level with support staff stating his engagement with day-to-day activities had improved. Sebastian's seizure frequency reduced by ~20%. Support staff and Sebastian's family reported his recovery time improved to 30 minutes, representing a 30% reduction in his recovery time. Sebastian's weight remained stable on his ketogenic feed. Sebastian's ketone readings remain consistent with levels between 2.3-3.0 mmol/L.

